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An anxious time? Exploring the worries experienced by people with
a mild to moderate intellectual disability at the stage of transition to
adulthood

&

Clinical Research Portfolio

PART 1

(Part 2 bound separately)

Marisa Forte

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Submitted in part fulfilment of the requirements for the Degree of
Doctor of Clinical Psychology

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Chapter 1

Systematic Literature Review

What is the impact of transition to adulthood on the perceived social status and self-determination of people with a mild to moderate intellectual disability?

Running title: Transition to adulthood for people with ID

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Abstract

Background: This systematic review investigates the impact of transition to adulthood on the perceived social status and self-determination of people with a mild/moderate

intellectual disability (ID). *Methods:* Published studies were identified through a systematic search of databases. Articles fulfilling inclusion criteria were rated for methodological quality. *Results:* Nine articles meeting inclusion criteria were reviewed. These studies indicated that young people with ID are aware of being part of a marginalised, low social status group. They have low self-determination, yet despite this are reasonably satisfied and manage to maintain future aspirations. This may be due to the range of social comparisons they make, although how they compare themselves to others showed contradictory findings. *Conclusions:* The contradictory findings highlight the need for high quality longitudinal research to examine young people's perceptions of their social experience throughout transition. Such research could play an important role in building resilience and self-determination.

Keywords: intellectual disability, self-determination, social comparison, future aspirations, transition.

Introduction

All young people face challenges at the stage of transition to adulthood, such as physical maturation (Hendren 1990), in addition to encountering social and emotional hurdles (Zeitlin *et al.* 1985). Key amongst these changes is growing self-determination and individuation, and the increasing importance of peer relationships. Peer relationships become more significant at this time as the young adults strive to become more autonomous and attempt to distance themselves from their family (Garbarino *et al.* 1987; Berndt 1979). Other changes in relationships that also often happen around this time are the development of first romantic relationships (Simmons and Blyth 1987). The young adult is expected to meet and accomplish these tasks of adolescence in addition to leaving school and starting work or further education (Ward *et al.* 2003). Successful achievement of these tasks of adolescence are important for psychological well being.

People with intellectual disabilities may face additional obstacles in achieving these tasks of adolescence due to the unique set of challenges posed by being a marginalised and stigmatised group. They are often likely to need continued and individualised support. Thus, in contrast to the typically developing young adult who is becoming more autonomous, the young person with intellectual disabilities often remains dependent. Additionally, people with intellectual disabilities often experience difficulties in negotiating, establishing and maintaining peer relationships (Carison 1987; Hoyle and Serafica 1988). As a result, this group may be more likely to face social exclusion which may make achieving the tasks of adolescence more difficult. This is important since if these tasks are not achieved and people perceive themselves as socially marginalised this may result in lack of autonomy, and the accompanying lack of social status and sense of

helplessness could make them more vulnerable to developing mental health problems (Einfeld and Tonge 1996).

Positive self-esteem, high self-efficacy and self-determination are all linked to well-being and high quality of life (LaChapelle *et al.* 2005). Individuals with intellectual disability often have a poor self-concept, resulting from awareness of being part of a marginalised and stigmatised group (Edgerton 1967; Reiss and Benson 1984; Jahoda *et al.* 1988).

Considering this groups awareness of stigma, as well as insight into their social, cognitive and behavioural difficulties it is understandable why people with intellectual disabilities may view themselves less favourably to others. A body of research has identified 'hierarchies of stigma' in which people with intellectual disabilities are known to make downward social comparisons to less able individuals or to those from other stigmatised groups in order to protect their self-concept (Goffman 1963; Gibbons 1985; Finlay and Lyons 2000). Despite this research, there has not been an attempt to draw the strands of literature together to examine how transition to adulthood and how changes in social and peer relationships make young people with ID *feel* about their social acceptance by peers and their subjective sense of self-determination at this stage. If this is a stage at which young people become more conscious of being socially marginalised and aware of their lack of social status then they might also compare themselves negatively with their non-disabled peers (Dagnan and Sandhu 1999). In a similar vein there is a view that a lack of self-determination at this stage of these young people's development could be associated with a sense of helplessness (Wehmeyer 2002). This systematic review will examine the experience reported by young people with intellectual disabilities themselves, and whether they do in fact report feeling increasingly marginalised and powerless as they make the

transition to adulthood, and whether the nature of reported experience is linked to a sense of well-being. There are two related bodies of work which will be examined: 1) the work on perceived social acceptance and social comparison of young adults with a mild/moderate intellectual disability, and how they perceive themselves in relation to others at this stage and 2) work on self-determination and future aspirations.

Research Questions. The specific questions that will be addressed in this are:

- 1) Does transition to adulthood affect perceived social status and social belonging/acceptance in people with a mild/moderate intellectual disability and is this associated with well being?
- 2) How does transition to adulthood impact on sense of self-determination and future aspirations for people with a mild/moderate intellectual disability and is this related to well-being?

Search Strategy:

Publications from peer reviewed journals were identified through use of the following methods:

Electronic and Bibliographic Search

An electronic search of the following databases was conducted: Ovid Medline (1950-2009, April, week 4); EMBASE (1967-2009, April, week 3); PsychINFO (1987-2009, May, week 1), and ERIC (1965 – 2009, May, week 1).

The following search terms were used: [Transition *or* Adulthood] and [Learning Disability *or* Intellectual Disability *or* Mental Retardation *or* Mental Deficiency *or* Mental Disability *or* Developmental Disability *or* Mentally Handicapped] and [Adolescence *or* Adolescent *or* teen *or* youth *or* young adult *or* young person *or* young people] and [quality of life *or* self-efficacy, *or* self-determination *or* sense of self *or* well-being *or* self-concept, *or* social comparison, *or* acceptance, *or* belonging *or* interpersonal *or* social relations *or* social inclusion *or* friendship *or* relationship *or* psychosocial *or* adjustment *or* psychological *or* emotion *or* future aspirations *or* goals).

Hand search of articles and key journals

In order to ensure all relevant journal articles were identified a search of the content pages and reference lists of the following journals were conducted: Journal of Learning Disabilities (2001-2008), British Journal of Developmental Disabilities (1999-2008), Child and Adolescent Mental Health (2005-2008), Journal of Intellectual Disability Research (1991-2008), Journal of Applied Research in Intellectual Disabilities (2002-2008), American Journal of Mental Deficiency (1980-2008), and Mental Handicap Research (1991-1995).

Inclusion and Exclusion Criteria:

Studies were included in this review if they examined social belonging/social acceptance, social comparison or self-determination at the stage of transition to adulthood and used quantitative methodology or descriptive statistics. Studies were only included if the young people in the sample were aged between 15 and 25 years and had a mild/moderate

intellectual disability. Crucial to this was that all included studies utilised self-report as opposed to informant based report. Additionally, all included studies were published in peer reviewed journals written in English and were published after 1991. Studies were included if the sample contained children less than age fifteen, although only if those people less than fifteen years were analysed as a differentiated group, for example in a cross-sectional study looking at different age groups. Studies which used qualitative methodology or whose main focus was on examining populations without an intellectual disability were excluded, as were dissertation abstracts, book chapters and conference proceedings.

Article selection

The abstracts of potentially relevant papers were read and full texts of all seemingly relevant papers were then examined and those suitable were identified. Unsuitable texts were discarded. A flowchart detailing the process of article selection is provided in Figure 1. Information was extracted on the following aspects of each paper which met inclusion criteria: clarity and focus of research question, study design, characteristics of the sample, transition factors, quality of measures used in assessment, main findings and methodological strengths and weaknesses.

Article quality and rating criteria

This systematic review draws on established guidelines, such as the CASP (Critical appraisal skills programme, 1993). However, since this review does not concern outcome studies only key criteria relevant to the type of study being examined will be used. Other

methodological factors will be considered in the narrative. Each of the papers that met inclusion criteria was ranked for quality using the criteria outlined in table 1.

[Insert table 1 about here]

As this review considers developmental change in participants' perception, studies were ranked primarily according to design. Longitudinal studies were rated highest, followed by cross-sectional with an age-matched control group or group comparison, then cross-sectional with no comparison group, then single sample designs at one time point (i.e. at one specific time point in transition) with a comparison group, and finally single sample studies at one time point in transition with no comparison group. Seven other factors (shown in table 1) were also given consideration and rated, and although studies were ranked primarily according to design, these other factors will be considered in the narrative. Studies which failed to meet criteria due to the design being inappropriate were discarded.

- Excellent (a score of 5 for study design)
- Very good (a score of 4 for study design)
- Good (a score of 3 for study design)
- Adequate (a score of 1 for study design)
- Inadequate (where the study design was inappropriate)

Summary of quality ranking of all included studies is shown in table 2.

[Insert table 2 about here]

Data Extraction

Following the application of inclusion and exclusion criteria, nine papers were identified as being relevant to the systematic review questions. Details of these nine papers are summarised in data extraction tables (tables 3, 4 and 5). The quality criteria above were applied to these studies by the first author and a second independent rater also applied ratings based on this quality criteria. Inter-rater agreement was 100%. One of the papers was rated as 'excellent', two were rated as 'very good', three were rated as 'good' and three were rated as 'adequate'. The remaining 53 papers were not included in this systematic review, either because they did not meet inclusion criteria, or because they met exclusion criteria. A summary of study exclusion categories in this review is shown in table 6.

Results

The first section addresses perceived social acceptance and social comparison. The second section concerns future aspirations and self-determination of young people with mild/moderate intellectual disabilities at the stage of transition to adulthood. There are two papers which deal with both social acceptance and self-determination, and these will be presented within the respective sections. Each of the above sections will begin with an outline of studies and findings before considering methodological strengths and weaknesses, and then outlining conclusions that can be drawn.

1) Social acceptance, belonging, and well-being.

Details of the 3 studies concerning perceived social acceptance and belonging (Chadsey-Rusch and Linneman 1997; Glenn and Cunningham 2001; and Bramston *et al.* 2005) are shown in table 3.

[Insert table 3 about here]

The Chadsey-Rusch and Linneman study (1997), which used a cross-sectional design with comparison groups was rated as ‘very good’ in this review. This study compared perceptions of social integration in a group of twenty-four young adults with ID who had left school and twenty-three young adults with ID who were just about to leave school. All of the young adults had worked at least for some of the time in integrated employment settings. A Likert style response questionnaire designed for this study required respondents to indicate their perception of factors important in social integration, and to rate factors which hindered social integration. Results showed that both groups of people with intellectual disabilities perceived the biggest barrier to social integration was having difficulty in learning new skills. Overall, the intellectual disability group rated themselves as reasonably satisfied with their social participation, workplace acceptance and personal acceptance, and feelings of social support. On the negative side, both groups of participants with intellectual disabilities felt that employers did not recognise the extra help and support they might need.

Glenn and Cunningham’s (2001), study was also concerned with perceived acceptance.

They utilised a single sample design at one time point in transition, although with no

comparison group. Their study was rated as ‘adequate’ in this review. Their study compared measures of self-acceptance, perceived competence, and self-esteem of 72 young people with Down Syndrome aged between 17 and 24 years. Participants completed either the Harter Pictorial Scale (Harter and Pike, 1984), which is a measure of social acceptance and perceived competence, or the Self Perception Profile for Learning Disabled Students (Renick and Harter, 1988). Results from both these measures showed that participants viewed themselves positively and perceived that they were accepted by their peers (Harter Pictorial Scale). On the Self Perception Profile, belief about self-worth was unrelated to perception of academic competence. There was a significant trend in the association between global self-worth and social acceptance, and global self-worth was correlated with physical appearance. This could have reflected the young people’s awareness of how they are perceived by others.

Similar to Chadsey-Rusch and Linneman’s (1997) study, the Bramston *et al.*(2005), study rated as ‘good’ in this review also utilised a single sample design at one time point in transition, although their control group had the benefit of being age-matched. Bramston *et al.* (2005), examined perceptions of social support, as well as factors important in determining perceptions of quality of life for transition age young adults. Measures of social support, neighbourhood belonging and stress were administered to two groups of young adults at transition age (16-23 years); one group with a mild ID recruited from a supported employment agency and a control group of volunteers recruited from a shopping mall. Results showed that the intellectual disability group reported poorer satisfaction with community involvement and with intimacy than the control group. The main predictor of perceived life satisfaction for both groups was social support. Regression analyses were

conducted to examine the influence of personal and environmental factors on perceived life satisfaction. It was found that emotional well-being and safety were significantly predicted by level of social support in both the intellectual disability group and comparison group. Social support also significantly predicted perceived satisfaction of material well-being for the intellectual disability group. ID participants reported being satisfied with their overall quality of life, but on the particular domains of intimacy and community involvement they expressed dissatisfaction, suggesting that they felt marginalised.

Methodological Strengths and Weaknesses

A strength of these studies is the attempt to adapt the self-report formats to make them more accessible and reduce biased responding. For example, Likert response formats were accompanied by visual aids (Finlay and Lyons, 2001) and practice items. This helped to ensure that the materials were salient and comprehensible. However, the Chadsey-Rusch and Linneman, (1997) paper only used a 3 point Likert scale, and Bramston *et al.* (2005), a 4 point scale, thus limiting range of response options to select from, and the interpretations that can be made. Only one of these samples used a large geographical cohort (Glenn and Cunningham 2001), while the other two papers had small sample sizes, and none made reference to power calculations. Although Bramston *et al.* (2005) was the only study to use an age matched control group, they were required to complete questionnaires on quality of life in a busy shopping mall, whereas the intellectual disability group completed their adapted versions of the measures in a quiet, private environment. This variability in data collection must be given consideration since others may have been present while the control group were completing measures which may increase likelihood of biased

responding. Importantly, two out of three of these studies only tested participants at a single time point in the transition process so results may not be generalisable to other time points at transition. Thus, although this allows us to see how these participants perceived their sense of belonging, acceptance and well-being at a specific time point they do not enable us to examine how this may change throughout the length of the transition process.

Conclusions

Two out of three of these papers utilised a single sample design at one time point so it is not possible to assign causality. These papers do however, show some interesting findings. All three papers indicated that the young people *were* aware of differences between themselves and others and of being part of a marginalised group. Despite this, the studies indicated that the young people with intellectual disabilities generally felt satisfied with their lives and their sense of well-being, although this depended on other factors, for example, well-being was linked to level of social support in the Bramston *et al* (2005) study. It is interesting that the ID group in the Chadsey-Rusch and Linneman (1997) study felt socially accepted and integrated, yet at the same time were aware of being part of a marginalised group who recognised that they needed extra help and support. This may mean that despite experience of marginalisation these young people feel resilient enough to cope, or it may mean that the questionnaire designed to measure satisfaction only allowed consideration of a limited aspect of people's experience.

1b) Social Comparison, self esteem and well being

Details of the 3 papers concerning social comparison and self-esteem (Szivos 1991; Szivos-Bach 1993; and Cooney 2006; and are shown in table 4.

[Insert table 4 about here]

Two of these papers (Szivos 1991; and Szivos-Bach 1993) were rated as ‘adequate’ in this review and one (Cooney *et al.* 2006) was rated as ‘good’.

Szivos, (1991), utilised a single sample design at one time point in transition with no comparison group. Fifty young adults with a mild ID and aged between 16 to 21 years were asked to compare themselves to a sibling, if they had one. Participants were required to select which of their siblings to compare themselves to based on the criteria of ‘similarity’ and ‘liking’. In general, participants saw themselves as similar to their siblings. However, there was a tendency for young people to perceive themselves as inferior to older siblings of the same sex and as superior to younger siblings of the opposite sex. Young people who reported the most experience of stigma had the lowest self esteem and viewed themselves more negatively in comparison to their siblings. Students with no sibling had more positive self-perceptions than students with a sibling.

In a follow-up paper Szivos-Bach (1993), utilised the same design to examine social comparison and self-esteem in fifty transition age intellectually disabled young adults. Participants were asked to identify certain categories of people to compare themselves to. These were: a friend, someone they knew with no intellectual disability, a sibling of their choice, and their perception of what they would ideally like to be like (‘their ideal’). Results showed that the young people perceived themselves as similar to their friends or another way of interpreting this is that they selected friends who they perceived to be like themselves. They viewed people with no intellectual disability as superior to them. There

was also a tendency for them to view older siblings of the same sex as superior to them, and for them to view younger siblings of the opposite sex as inferior. Those with more experience of stigma had lowest self-esteem, and were most likely to view themselves negatively compared to other typically developing people. The young people with the highest self-esteem had the highest targets of what they would ideally like to be like and had least awareness of stigma.

Cooney *et al.* (2006) also used a single sample design at one time point although they used a comparison group. Cooney *et al.* (2006), were also concerned with the social comparisons people with ID make. They examined the perceived stigma and social comparison among 60 young people with a mild intellectual disability in their final year of mainstream versus segregated secondary schooling. Participants completed measures of social comparison, and were asked about their experience of stigma. They found that regardless of type of school attended (segregated or mainstream) both groups compared themselves favourably to a more disabled peer, and also compared themselves more favourably to a non-disabled peer. Cooney *et al.* (2006) also found that both groups reported experiencing a considerable degree of stigma and although the mainstream group were found to face additional stigma at school, both groups reported experiencing a substantial degree of stigma outside of school. These results indicate that the young people with intellectual disabilities did feel marginalised, but also that they managed to maintain a positive sense of self, despite this.

Methodological Strengths and Weaknesses

With respect to the measures of social comparison and self-esteem, all three of these papers have utilised adapted measures to suit the needs of the population. Although many measures have not been standardised specifically for those with an intellectual disability, considerations were made to ensure the measures used were salient to the population, and had been used before. Cooney *et al.* (2006) found that reliability was problematic on the social comparison measure when individuals were comparing themselves to a non-disabled peer, however when it was used to compare themselves with a disabled peer the measure was more reliable. With regard to the measure of IQ, all three studies used the British Picture Vocabulary Scale (BPVS) as a measure of the participant's IQ. Some consideration should be given to this, since the BPVS is only a single assessment of verbal comprehension. Cooney *et al.* (2006) found that the BPVS lacked sensitivity at the lower end of the scale, and this produced a floor effect. Szivos-Bach (1993) also reported some difficulties with the BPVS, finding that some students scored lower than expected, due to test anxiety, while others scored higher than expected thus casting some doubt on the reliability of the results, due to the range of IQ scores obtained. A further point of note is that the papers by Szivos (1991) and Szivos-Bach (1993) both asked the participants to choose the people to compare themselves to, for example the criteria for choosing the sibling to compare themselves to was 'liking and similarity', thus it is not that surprising that the young people perceived themselves as similar to their sibling.

Conclusions

All of these studies were a single sample design at one time point so once again they only examined the variables of interest at one time point in transition and only Cooney *et al.* (2006) had an age matched control group. Therefore, it was not possible to examine

differences in perceived social status over time, in order to ascertain how these perceptions may change during transition to adulthood. These papers show some contrary findings with regard to social comparison. On the one hand Szivos (1991) and Szivos-Bach (1993) found that the young people had a tendency to perceive themselves as superior to siblings of the opposite sex and inferior to siblings of the same sex, while Cooney *et al.* (2006) found that the young people always compared themselves positively to others. This suggests that the nature of at least some of these comparisons are quite idiosyncratic: in other words the comparisons that people make appear to depend on who the young person compares themselves to. As social comparison was found to be linked to self-esteem, this indicates that who the young people choose to compare themselves to will be likely to have an impact on their sense of well-being.

These three studies also indicate that young people with an intellectual disability are aware of being part of a marginalised group with low social status who experience considerable stigma. Considering this, it is unsurprising that these young people may compare themselves negatively to others. What cannot be answered from these papers is the nature of the social comparison process and whether past experience of stigma has an influence on whether these people are using social comparison as a protective mechanism for maintaining sense of self.

Future aspirations and self-determination:

This section will examine papers relating to future aspirations and self-determination in people with a mild/moderate intellectual disability at the stage of transition to adulthood. The relevant parts of two papers discussed earlier will be reviewed (Szivos-Bach 1993; and Cooney, *et al.* 2006), in addition to three further studies (Wehmeyer 1994; Casey *et al.* 2006; and Wehmeyer *et al.* 2006). Therefore this section concerns 5 papers in total. Details of these papers are shown in tables 4 and 5.

[Insert table 5 about here]

Szivos-Bach's (1993) study examined future aspirations and expectations of transition age young adults. Aspirations were measured by a specially designed questionnaire drawing inspiration from results of an anthropological study concerning the experience of stigma (Edgerton, 1967). Students in Szivos-Bach's (1993) study were required to rate both their aspirations and expectations on a three point Likert scale. Results showed that neither the participants' aspiration score nor their expectation of achieving their aspirations were related to IQ, sex, or age. There was a trend towards young people with work experience having higher aspiration ratings. Highest aspiration ratings were concerning getting a job. Young people who were most segregated had a tendency to view themselves as being most likely to fulfil their future aspirations, and people who had most experience of stigma had the lowest expectation that they would achieve their future aspirations. High aspirations were also linked to high perception of their ideal self, i.e. what they would 'like to be like'.

In contrast, Wehmeyer's, (1994) study examined locus of control, self-determination, self-efficacy, and future expectations and aspirations in a cross-section of adolescents aged from thirteen to twenty years. This cross sectional design was rated as 'very good' in this review

as it enabled some interpretation of how self-efficacy and self-determination change in relation to development. Results showed that there was a decreased linear trend in self-efficacy scores as age increased: self-efficacy was highest in young adolescents and was lowest in those aged between 18 to 20 years. The authors thought that lower self-determination was linked to an external locus of control. In other words those with intellectual disabilities were less likely to see themselves as the ‘causal agent’ in their own lives, but were likely to believe that external sources, such as luck, and fate determined how they would fare.

Also examining future aspirations but using a single sample design from one time point in transition with a comparison group was the Casey *et al.* (2006), study, rated as ‘good’ in this review. This study examined the influence of schooling on future aspirations of 604 young people with an intellectual disability and aged between 15 and 16 years in their final compulsory year of school. Young people with a mild intellectual disability who were educated in a mainstream school were more likely to aspire to employment of a higher status than those educated in segregated schooling. Those from mainstream school who wanted to continue in post-16 education were more likely to aspire to a higher level course than those from segregated schooling. Young people who were educated in mainstream schools were more likely to want to live independently from their family, than those who were educated in segregated schooling.

In a similar vein to Casey *et al.* (2006), Cooney, *et al.* (2006), also looked at aspirations in segregated versus mainstream school. They asked participants to complete the Future Aspirations Checklist (Halpern 1994), a three item scale which examines future

autonomous living and employment goals of people with an intellectual disability. Results showed no significant difference between segregated and mainstreaming schooled students in their beliefs about their ability to attain future goals. The future aspiration of most participants in both schooling groups involved living autonomously. More of the mainstream educated group aspired to obtaining a professional job. Participants' previous experience of stigma was not found to be correlated with their confidence about achieving their future aspirations.

Taking a different approach, the Wehmeyer *et al.* (2006), study rated as 'excellent' in this review, evaluated a training programme to increase self-determination in transition age youths. This was the only study which utilised a longitudinal design. Young people with an intellectual disability aged 18-21 years completed 3 measures: The Goal Attainment Scale, a self report version of the Autonomous Functioning Checklist and the Arc Self-determination Scale. Scores were recorded pre and post training on the self-determination training model. Scores on the Autonomous Functioning Checklist increased following training on the self-determination model, with results showing a significant difference on three out of four domains of this checklist: self and family care, management, and recreation and leisure. Pre and post test scores were not significantly different on the fourth domain of this checklist which was sense of autonomy regarding social and vocational activities. There was no significant difference pre and post test on scores for the Arc's self determination scale and level of self-determination was low. Results of the Goal Attainment Scale indicated over half the goals had been met at a satisfactory level, with the highest mean score of goals for social relationships.

Methodological Strengths and Weaknesses

A strength of the study by Wehmeyer *et al.* (2006) was the longitudinal design, since measures of self-determination and autonomous functioning were carried out with participants pre and post training on a model to promote self-determination. However, there was no control group and the sample size was very small, therefore it is difficult to generalise the findings. A lack of information was provided about the training and it was also unclear how long the training lasted. Wehmeyer's earlier (1994) study which utilised a cross-sectional design allowed examination of perceptions of self-determination and self-efficacy in different age groups. However, it did not have the benefit of looking at the *same* group over the entire length of the transition period. The other three studies only looked at one specific time point in transition thus findings may not be generalisable. However, there are other strengths of note. The Casey *et al.* (2005), study is the largest study in Britain to date which has examined future aspirations of people with an intellectual disability. Another innovation by Casey *et al.* (2006) was using an independent specialist polling company to collect their data. This method of data collection ensured that a more representative sample was obtained. Participants may also have understood that those collecting data were not connected to services, thus reducing the risk of response bias or participants giving answers they thought the professional would want to hear.

Conclusions

With regard to the future aspirations of individuals with an intellectual disability at the stage of transition to adulthood these studies show some similar findings. Both Cooney *et*

al. (2006), and Casey *et al.* (2006), found that those educated in mainstream school were more likely to aspire to attaining a professional job, while those educated in segregated schooling were more likely to aspire to a manual or blue-collar type job. However, what these studies do show is that all participants aspired to having a job regardless of type of schooling.

Living autonomously was ranked as being an important aspiration to all, although this was rated as more important to mainstream pupils in the Casey *et al.* (2006) study.

Contrasting results were found with respect to the effect of type of schooling on perception of ability to attain future goals. Cooney *et al.* (2006), and Casey *et al.* (2006) found that whether individuals were educated at mainstream or segregated schooling did *not* influence perception of ability to attain their future goals, or likelihood of achieving those goals. In contrast, Szivos-Bach (1993) found that those in segregated schooling were more optimistic about attaining their future goals.

There were also contrasting results with regard to the relationship between stigma and perception of ability to achieve future goals, Szivos-Bach (1993) found those with most experience of stigma were least likely to achieve future aspirations, while Cooney *et al.* (2006), found experience of stigma was unrelated to perception of ability to achieve future goals.

The studies reviewed concerning self-determination (Wehmeyer 1994; and Wehmeyer *et al.* 2006) indicate that people with an intellectual disability have low self-determination at the stage of transition to adulthood. Although the findings from Wehmeyer *et al.* (2006)

show that goals mostly relating to social relationships were reached following instruction on the self-determination model, there was no difference in sense of self-determination scores pre and post training. This suggests that even if goals are reached, the sense of self-determination remains low for individuals with an intellectual disability at the stage of transition to adulthood.

What we can again conclude from these papers is that young adults with a mild intellectual disability do report feeling marginalised and have considerable experience and awareness of stigma. However, despite this awareness, the young people remained quite positive about their future aspirations.

Discussion

This systematic review examined the available literature on how transition to adulthood affects perceived social status and acceptance in people with a mild to moderate intellectual disability, and the effects of these perceptions on well-being. The review also examined the available literature on how transition to adulthood affects sense of self-determination and future aspirations in transition age youths. However, only one of the studies adopted a longitudinal design, and even then the follow-up was for a short unclearly defined period. One further study adopted a cross-sectional design while the majority utilised samples at a single time point in transition. Therefore, we cannot definitively conclude how people's social acceptance and sense of self-determination *changes* during the transition period or how sense of well-being is affected throughout the *entire* transition period.

However, these papers do show some interesting findings. First of all, it is apparent that these young people report experiencing considerable stigma and are aware of being part of a marginalised, low social status group. Interestingly, in spite of this awareness of marginalisation the studies reviewed indicate that the young people were reasonably satisfied with their lives, and also importantly, that they were able to maintain a sense of having future aspirations, despite facing this considerable stigma. It is interesting to consider why this might be the case. It may be to do with the social comparisons that this group make. A body of research shows that people with intellectual disabilities often make downward social comparisons. It has been suggested that this may be in an attempt to protect their self-esteem in the face of stigma (Goffman 1963), with other work showing similar results in adults who have an intellectual disability, (Dagnan and Sandhu 1999). The studies in this review found that the young people viewed themselves as superior to some people yet inferior to others. One possible explanation for this could be that in spite of having various ‘reference groups’ with which to compare themselves to, individuals with intellectual disabilities may afford more weight to some comparisons over others and the ones that they place more emphasis on may be the ones that serve to protect their self-esteem. The finding that individuals perceived themselves as inferior to *older* siblings but as superior to *younger* siblings is also interesting. In terms of social comparison, this may be because older siblings might be seen as someone the young person can depend on and someone to look up to, whereas younger siblings who may be overtaking them in developmental milestones may have social opportunities which serve to remind the intellectually disabled person of their difficulties and marginal social status.

The studies reviewed here support a larger body of work which shows a link between self-determination and self-esteem in people with intellectual disabilities (e.g. LaChapelle 2005). In the main, these studies found that young people who had lowest self-esteem had most experience of failure and most awareness of being a marginalised group. It is therefore understandable why these young people tended to have an external locus of control and low sense of self-determination, as they *are* often uncertain what the future holds for them and this is compounded by the fact that they have limited choice compared to significant others in their life and within service systems. The finding that work was rated as an important aspiration in all of the studies which examined future aspirations may be to do with the idea that work is seen as ‘valued’ in this society and may also be linked to the person with an intellectual disability having a job as proof of their ‘normality’, and this may take on greater importance for those with intellectual disabilities.

With these studies suggesting that self-determination is low in these young people it is uplifting to note that some aspects of autonomous functioning increased following training on the model to enhance self-determination in the study by Wehmeyer *et al.* (2006). This supports a larger body of work on positive adult outcomes and enhanced quality of life being linked to high self-determination (Wehmeyer and Palmer 2003). What is also optimistic is that the studies reviewed indicated that these young people maintained future aspirations at some level suggesting that there is resilience with these young people that can be worked upon.

Limitations

This systematic review only included studies in which participants were over fifteen years of age, or where a sub sample of participants of a wider age range were over fifteen years and were analysed separately. This decision was made as the author believed it was important to capture the specific time period of leaving school and making the transition to adult life. However, taking account of a broader age range could provide greater insight into the transition process. This might start with young people at the onset of puberty, and continue until the tasks of adolescence are complete and adulthood is achieved. This would allow further exploration of developmental changes in young people's sense of social acceptance, self-determination and well-being.

Further longitudinal research is vital, if we are to gain a better understanding of ways in which we can improve these young people's sense of resilience to cope with such marginalisation. This should involve work on improving people's sense of self-determination alongside an effort to offer more real-life opportunity for this, such as in employment. A further benefit of increasing sense of self-determination would be that vulnerability to developing mental health problems may be reduced. Future research of this nature also has to try to obtain the experience of young people themselves rather than using informant report.

To conclude, this review suggests that young people with an intellectual disability report a reasonably positive sense of well-being and are satisfied with their quality of life. However, despite feeling reasonably satisfied with life at the stage of transition to adulthood, people with mild to moderate intellectual disabilities continue to feel marginalised and believe that they have limited opportunity to shape their future. The studies also indicate that people use

mechanisms to maintain a positive sense of self, such as social comparison. Finally they indicate that these young adults are able to maintain future aspirations at some level.

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Table 1: Quality Criteria and Ranking System

STUDY QUESTION:	Focussed with clear aims	4
	Partially focussed	3
	Not clear	0
STUDY DESIGN:	Longitudinal	5
	Cross sectional with an age matched control or group comparison	4
	Cross sectional (with no age matched control and no group comparison)	3
	Single sample design from 1 time point in transition (with comparison group)	2
	Single sample design from 1 time point in transition (no comparison group)	1
SAMPLE REPRESENTATION:	Geographical cohort	4
	Random sample (but not geographical cohort)	3
	Convenience sample	2
	Volunteer sample	1
	Unclear how sample was obtained	0
SAMPLE DEMOGRAPHICS:	Age, gender, SES, and level of ID reported	4
	Any three of the above reported	3
	Any two of the above reported	2
	Only one of the above reported	1
TRANSITION FACTORS:	Stage of transition clearly reported	4
	Between 15-25 yrs but transition stage not reported	3
MEASURES OF SELF-CONCEPT/SELF DETERMINATION/SELF-EFFICACY	Standardised and/or Valid and reliable measure for use with ID population	4
	Measure normed on non-ID population, appropriate to design and adapted and for use with ID population	3
	Non standardised measure appropriate to design and use for ID population (inc. an appropriate questionnaire with specifications made)	2
	Measure inappropriate to design or population	0

MEASURE OF INTELLECTUAL DISABILITY	Standardised measure of IQ (e.g. WAIS) 4
	BPVS or only measure of adaptive functioning 3
	Review of case notes +/- or how ID was reported. 2
	Not specified 1
INFORMANT INFORMATION	Completely subjective ratings 4
	Mostly subjective ratings (i.e. carers were present and may have provided some help when needed) 2

Table 2: Quality ranking of all included studies

Study	Study Quest.	Study design	Rep. of sample	Sample demographics	Transition factors	Established measure /adequateness of measure	ID measure	Informant/ Self-ratings	Category (adequate, good, excellent)
Szivos (1991)	4	1	2	3	3	2	3	4	adequate
Szivos-Bach (1993)	4	1	1	3	3	2	3	4	adequate
Wehmeyer (1994)	4	4	2	2	3	3	2	4	very good
Chadsey-Rusch and Linneman (1997)	4	4	2	3	4	2	1	4	very good
Glenn and Cunningham (2001)	4	1	4	3	3	3	3	2	adequate
Bramston <i>et al.</i> (2005)	4	2	1	3	3	4	2	4	good
Cooney <i>et al.</i> (2006)	4	2	1	4	4	2	3	4	good
Casey (2006)	4	2	4	3	4	2	2	2	good
Wehmeyer, <i>et al.</i> (2006)	4	5	2	3	3	3	1	2	excellent

*Independent inter-rater agreement of quality of studies was 100%

Table 3: Data extraction table: Included studies relating to social belonging/acceptance.

Study author, quality rating and design	Variables considered	Sample characteristics	Measures	Main Results	Methodological issues
<p>Chadsey-Rusch and Linneman (1997)</p> <p>Cross-sectional design with group comparisons.</p> <p>(rating: very good)</p>	<p>Social integration into the workplace.</p> <p><u>Aims of study:</u> to examine what is understood as being important in social integration by multiple groups (including employers and job coaches, and 2 ID groups (1 ID group still at school and 1 ID group who had left school). All ID participants had some experience of working in integrated employment settings.</p>	<p>Convenience sample. 5 groups of individuals took part in this study, including a group of young adults with ID still attending school, but about to leave (n=23), another group of ID young adults who had already left school (n=24). Total ID sample (n=47).</p> <p>83% of the 'still at school' group and 61% of the 'out of school' group had a mild ID (the remainder had a moderate ID). Mean age of young ID adults still at school =17.5 years; mean age of students who had left school = 25 years).</p> <p>'still at school' ID group = 65% female, 35% male. 'out of school' ID group = 54% female, 46% male.</p>	<p>Clinical Questionnaire designed for study. Participants were asked to indicate their agreement (on a scale) relating to factors which they perceived may improve social integration. Participants were additionally asked to select from a list of 6 barriers which they viewed may hinder social integration.</p> <p>Question formats for ID group were yes/no and multiple choice in structure, and questions were presented both in the positive and negative form, to minimize biased responding. Participants had to indicate their responses by pointing to Likert pictorial representations of faces.</p>	<p>Both ID groups perceived that the biggest barrier to them feeling socially integrated was employers not recognizing that due to the nature of their ID they may experience difficulties in learning new skills. Both ID groups perceived barriers to social integration as being more significant than employers.</p> <p>Both ID groups felt reasonably satisfied about social acceptance, personal acceptance and workplace acceptance.</p>	<p>Practice items of measures helped to ensure ID groups understood task and pictorial representation format was useful.</p> <p>Response format on the questionnaire was small to facilitate ease of responding by ID groups, but there is the possibility that this may have restricted response options and variability of responses.</p> <p>Small sample.</p>

Table 3: Data extraction table: Included studies relating to social belonging/acceptance.

Study author, quality rating, and design	Variables considered	Sample characteristics	Measures	Main results	Methodological issues
<p>Glenn and Cunningham (2001)</p> <p>Single time point sample (at 1 time point in transition) with no control group)</p> <p>(rating: adequate)</p>	<p>Self esteem, self acceptance and perceived competence in people with Down Syndrome (DS) at the stage of transition to adulthood.</p>	<p>Geographical cohort: Young adults with Down Syndrome (DS) (n=72, age 17-24 years).</p>	<p>Measure of ID = BPVS-11</p> <p>‘Harter Pictorial Scale’ (Harter and Pike, 1984)</p> <p><i>or</i></p> <p>‘Self perception profile for LD students’ (Renick and Harter, 1985)</p> <p>(the choice of which measure was administered was dependent upon which measure participants could manage to complete, e.g. self perception profile was used if participants could cope with the attentional demands of the measure)</p>	<p>Most people rated themselves very positively and perceived they were accepted by peers.</p> <p>Significant trend in the association between global self-worth and social acceptance. Global self worth was correlated with physical appearance.</p> <p>Perception of self-worth unrelated to academic competence.</p>	<p>BPVS II: Participants’ IQ’s were interpreted on the basis of only one assessment of verbal comprehension.</p> <p>Self report in the majority of cases but parents were present for some participants, thus introducing possibility of biased responding/help being provided.</p> <p>Scales had good validity, and internal consistency, supporting reliability.</p> <p>Study only looked at one specific time point in transition process (not generalisable).</p>

Table 3. Data extraction table: Included studies relating to social belonging/acceptance.

Study author, quality rating, and design	Variables considered	Sample characteristics	Measures	Main results	Methodological issues
<p>Bramston <i>et al.</i> (2005)</p> <p>Single time point design with non-ID age-matched control group.</p> <p>(rating: good)</p>	<p>Study examined quality of life variables 1) stress, 2) social support, and 3) neighbourhood belonging in a transition age sample:</p>	<p>Community based sample of young adults with mild ID. Total group: n=200, aged between 17-25 years. ID group: n= 80 and non ID controls: n= 120</p>	<p>Comprehensive Quality of Life Scale (Cummins, 1992)</p> <p>Lifestress Inventory (Bramston <i>et al.</i> 1999)</p> <p>Neighbourhood Youth Inventory (Chuipei <i>et al.</i> 1999)</p> <p>Social support scale (Cutrona and Russell, 1987)</p>	<p>ID group perceived lower satisfaction with intimacy and community involvement than control group.</p> <p>Level of social support was the strongest predictor of life satisfaction across both groups.</p> <p>Safety and emotional well-being significantly predicted by level of social support in both ID and non-ID groups.</p> <p>In ID group level of social support significantly predicted perceived satisfaction of material well being.</p>	<p>Strategies to reduce response bias effects, e.g. 1:1 interview with ID, utilizing significant events as markers, and checking of words/concept comprehension, as well as use of visual aids to ease understanding of Likert scale response formats.</p> <p>But, variation in data collection procedures between the 2 groups.</p> <p>Study looked at a single time point in transition (not generalisable).</p>

Table 4: Data extraction table: Included studies relating to social comparison.

Study author, quality rating, and design	Variables considered	Sample characteristics	Measures	Main results	Methodological issues
<p>Szivos (1991)</p> <p>Single time point design (at one point in transition process) with no comparison group</p> <p>(rating: adequate)</p>	<p>Self esteem, perception/experience of stigma, and social comparison/how people with ID viewed themselves in relation to their siblings.</p>	<p>Convenience sample: young adults with mild ID (n=50, age 16-21 years, m=20, f=30) all were participating in courses attached to FE colleges in England.</p>	<p>Level of ID: BPVS</p> <p>Social Comparisons scale</p> <p>The Stigma Scale</p>	<p>People with ID viewed themselves as similar to their siblings but there was a tendency for them to view themselves as inferior to older siblings of the same sex and as superior to younger siblings of the opposite sex.</p> <p><u>Stigma</u>: Individuals with the most experience of stigma had the lowest self esteem. Those who perceived most experience of stigma viewed themselves as inferior to their siblings.</p> <p>People with ID who compared themselves with siblings of the same sex were more anxious than those who compared themselves to siblings of the opposite sex.</p>	<p>Participants IQ's were interpreted on the basis of a single assessment of verbal comprehension (BPVS)</p> <p>The criteria for selecting the sibling to compare themselves to were 'liking and similarity to the student', which may explain why they perceived themselves as similar to their sibling.</p> <p>Study looked at single time point in transition (not generalisable).</p>

Table 4: Data extraction table: Included studies relating to social comparison and future aspirations.

Study author, quality rating, and design	Variables considered	Sample characteristics	Measures	Main results	Methodological issues
<p>Szivos-Bach (1993)</p> <p>Single time point design (at 1 time point in transition) with no comparison group.</p> <p>(rating: adequate)</p>	<p>Self esteem, future aspirations, social comparisons.</p> <p>Aims of study: to measure self esteem and social comparisons between the way the ID individual saw themselves in relation to friends, siblings, non-ID, and how they would ideally like to be. Also measured stigma and future aspirations</p>	<p>Volunteer sample: students with ID (n=50, f=20, m=30). All were students at courses attached to FE colleges in England and all were in the process of undertaking a course relevant to experience when leaving school.</p>	<p>BPVS to measure IQ</p> <p>Social comparisons test</p> <p>Stigma Questionnaire</p> <p>Aspirations and expectations (questions drawn from Edgerton, 1967) for Aspirations and Expectations test.</p>	<p><u>Comparison:</u> ID viewed themselves as similar to friends (with ID) and 'others' who did not have an ID as superior.</p> <p>People with ID had a tendency to view themselves as superior to opposite sex siblings. They saw themselves as superior to younger siblings of the opposite sex and inferior to older siblings of the same sex.</p> <p><u>Aspirations:</u> ID students with highest self esteem had highest ideals.</p> <p><u>Stigma:</u> ID students with highest self esteem and highest ideals showed least awareness of stigma. Students who perceived the most stigma also perceived themselves as most inferior to their comparison targets (non ID, others, siblings and ideals).</p>	<p>BPVS was the only measure used to estimate intellectual ability. Author notes difficulties with this in the study: some performing lower than expected due to test anxiety and some performing higher due to receptive language abilities being higher than other abilities.</p> <p>Study looked at single time point in transition (not generalisable).</p>

Table 4: Data extraction table: Included studies relating to social comparison and future aspirations.

Study author, quality rating and design	Variables considered	Sample characteristics	measures	Main results	Methodological issues
<p>Cooney <i>et al.</i> (2006)</p> <p>Single sample (at one point in transition) with comparison group.</p> <p>(rating: good)</p>	<p>Perceptions of experience of stigma. Social comparisons made by people with a mild/moderate ID from either mainstream or segregated schooling.</p> <p>Likelihood of attaining future goals was also measured.</p>	<p>Volunteer sample of adolescents with ID aged between 15-17 years (m=31, f=29), in their final year of compulsory secondary schooling in Scotland (total group, n=60, 28 from mainstream school and 32 from segregated schooling)</p>	<p>Level of ID: BPVS-r</p> <p>Adapted social comparison scale (Dagnan and Sandhu, 1999)</p> <p>Modified Life School checklist (Arora, 1987)</p> <p>Experiences of Stigma Checklist (specially developed for study)</p>	<p><u>Stigma:</u> participants reported experiencing a considerable degree of stigma (mainstream group reported experience of extra stigma at school but both groups experienced out of school stigma). Self report of stigmatised treatment not sig. correlated with views of likelihood of attaining future goals/ difficulty in attaining future goals.</p> <p><u>Comparisons:</u> Both ID groups perceived themselves positively in relation to a more disabled peer and to a non-disabled peer. No significant difference in social comparisons that were made between ID from segregated and mainstream schools.</p> <p><u>Aspirations:</u> Mainstream pupils had higher aspirations. Both groups perceived it likely they would attain future goals. Work seen as important aspiration by both groups.</p>	<p>Participant's IQ's determined on basis of BPVS: one assessment of verbal comprehension.</p> <p>Segregated group came from significantly more deprived areas than mainstream group (although SES was not found to affect dependent variables). Age matched control group.</p> <p>Measures had low reliability, e.g. Social comparison measurement with a non-disabled peer was significantly less reliable than for comparison with a more disabled peer.</p> <p>Large numbers of suitable participants declined to participate.</p> <p>Study looked at a single time point in transition (not generalisable).</p>

Table 5: Data extraction table: Included studies concerning self-determination and future aspirations.

Study authors, quality rating, and design	Variables considered	Sample characteristics	Measures	Main findings	Methodological considerations
<p>Wehmeyer (1994)</p> <p>Cross sectional design. with group comparison</p> <p>(rating: very good)</p>	<p>Perceptions of self-efficacy, locus of control, and future outcome expectancies were examined.</p>	<p>Convenience sample: 282 students with ID. Groups of participants aged 13-20 years. Differentiated group stats on 15-18 yr age group. (m=58% of sample, f=42% of sample). Further analysis compared this group to no disability group (n=26) and students with learning difficulties (total n for the further analysis =53).</p>	<p>Self efficacy scale and the Outcome Expectancy Scale (Ollendick et al, 1986).</p> <p>Adult Norwicki-Strickland Internal-External scale (ANS-IE) (Norwicki and Duke, 1974) (general locus of control scale)</p> <p>Intellectual Achievement Responsibility Questionnaire (IARQ) (Crandall et al, 1965) (measures student beliefs in responsibility for success and failure).</p>	<p>Decreased self-efficacy as a function of age.</p> <p>Significant differences on perceptions on locus of control between ID group and students with no disability. Students with ID did not have beliefs which facilitated them to become the 'causal agent' in their own life (Wehmeyer)</p> <p>Over time (from age 13) there was a decrease in efficacy expectations, although outcome expectancies did not drop. By age 18, efficacy expectations and outcome expectancies were almost identical. Only Self efficacy scores changed significantly over time, but in the opposite way to hypothesised.</p>	<p>Benefit of cross-sectional design.</p>

Table 5: Data extraction table: Included studies relating to social belonging/acceptance.

Study authors, quality rating, and design	Variables considered	Sample characteristics.	Measures	Main findings	Methodological considerations
<p>Casey <i>et al.</i> (2006)</p> <p>Single time point design (at 1 point in transition) with a comparison group</p> <p>(rating: good)</p>	<p>Aims of study: to examine the effect of mainstream and segregated schooling on the future aspirations of people with a mild ID. All participants were in their final year of compulsory secondary school in England.</p>	<p>Large geographical cohort. Total participants: n=1005 (65% male; 35% female), with mild ID group differentiated (n=604) from those with other special educational needs. All 604 participants were aged 15 or 16 years, in their final year of school.</p>	<p>Specially designed interview/questionnaire to gather data on future aspirations and expectations.</p>	<p>People with ID in segregated schooling were more likely to continue in education, whereas those in mainstream schooling were more likely to try to find work.</p> <p>Young ID at segregated school were more likely to have future aspirations relating to obtaining manual jobs than those in mainstream. Those in mainstream had aspirations of a higher status. Those educated in mainstream school were more likely to want to live autonomously and aspire to having their own children. Pupils with ID in mainstream were more likely to be certain of their future aspirations.</p>	<p>Questionnaire designed for study, rather than measure previously used on ID participants.</p> <p>No measure of ID used in study (relied upon informant report and school records).</p> <p>Study looked at single time point in transition (not generalisable), but a large geographical cohort of participants.</p>

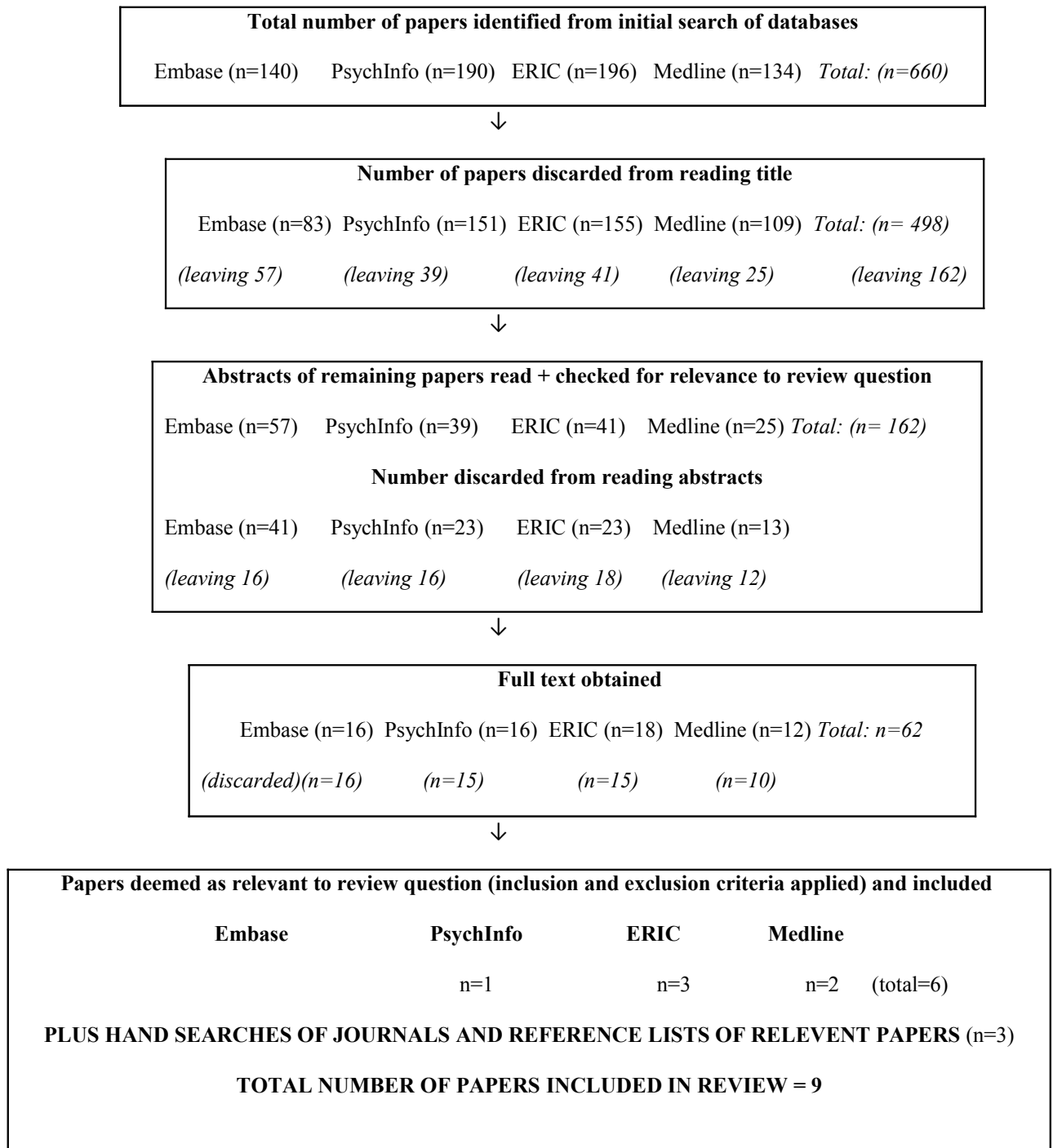
Table 5: Data extraction table: Included studies relating to self-determination and future aspirations.

Study authors, quality rating, and design	Variables considered	Sample characteristics	Measures	Main findings	methodological issues
<p>Wehmeyer <i>et al.</i> (2006)</p> <p>Longitudinal design</p> <p>(rating: excellent)</p>	<p>Self determination, goal attainment, and autonomous functioning.</p> <p>Pilot evaluation of a model to promote self determination in 18-21 services for those with ID. Model called 'beyond high school.' This study examined the impact of self-determination training on student self determination and autonomy (measures taken pre and post training on the model).</p>	<p>Community based convenience sample of: young adults with ID (n=15). All were at the stage of transition to adulthood (m=8, f=7).</p>	<p>Arc's Self Determination Scale (Wehmeyer and Kelchner, 1995b)</p> <p>Autonomous Functioning Checklist (inc. sub scale of social and vocational activity and recreational activity (Sigafoos, 1988))</p> <p>Goal Attainment Scale (GAS)</p>	<p>No significant differences between pre and post treatment scores (Arc's self determination scale). Significant differences found on 3 out of 4 domains on the autonomous functioning checklist.</p> <p>Pre and post test measures indicated that the young adults viewed themselves as having increased autonomy after training in the transition model.</p> <p>ID students involved in the training were very successful in achieving self set goals, especially those relating to social relationships. A score of >50 on GAS indicated student performed satisfactorily. Mean score post test was 51.55.</p>	<p>Small sample, although benefit of longitudinal design</p> <p>No control group (therefore it is difficult to assign causality to the training on the model, so findings cannot necessarily be generalised).</p> <p>Socio-economic status not reported.</p> <p>No measure of treatment fidelity.</p> <p>Not clear how long training on the model lasted.</p>

Table 6: Summary of study Exclusion Categories

Reason for Exclusion following reading of abstracts and full text: (162 studies) number of studies (%)	
Review/report/book chapter	25 (15%)
Study used qualitative methodology and/or was not self report	49 (30%)
Study did examine transition but not in relation to the study question/different transition (e.g. transition to older adulthood or sample included youths < 15 years)	38 (24%)
Transition but no disability, not intellectual disability, or if sample contained ID's they were not a differentiated group	50 (31%)
Total number of studies where abstracts were obtained	162 (100%)

Figure 1: Flowchart of search strategy and results



Chapter 2

Major Research Project

An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood.

Running title: Worries at transition for young people with ID.

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Structured Summary

Background: This exploratory study examined the content and salience of worries experienced by young people with mild intellectual disabilities (ID) at transition to adulthood. Self-efficacy and anxiety in relation to worry was also examined. Fifty-two participants (17-20 years) took part; 26 with mild ID and 26 typically developing adults. Participants were recruited from a college in Glasgow.

Materials and Methods: Of interest were potential differences between groups in i) worries described, ii) salience of worries, and iii) relationship between self-efficacy, anxiety, and worry within groups. Participants completed a ‘worry’ interview, the General Self Efficacy Scale-12, Glasgow Anxiety Scale-LD, and Wechsler Abbreviated Scale of Intelligence.

Results: People with ID identified different worries from typically developing people. There were also significant differences in rumination and distress between groups, and associations between anxiety and distress.

Conclusions: Obtaining insight into worries at transition may facilitate guidance opportunities. Clinical applications of the findings are discussed.

*Keywords :*intellectual disabilities, transition, worry,

Introduction

Although there is a large amount of literature concerning worry content in the general population (Borkovec *et al.* 1983; Craske *et al.* 1989) there has been little work on the nature and salience of worries experienced by individuals with a mild intellectual disability (ID). Borkovec *et al.* (1983) conceptualised ‘worries’ as ‘a chain of thoughts and images which are negatively affect laden and relatively uncontrollable’. To engage in ‘normal’ amounts of worry is regarded as adaptive and positive, and is recognised as something that we all do to a greater or lesser degree (Wells 1995). For example, worrying can help us be attentive to threat, therefore reducing the ‘unexpectedness of an aversive event by facilitating coping’ (Mathews 1990). However, chronic and repeated worrying can be maladaptive, such as in Generalised Anxiety Disorder, where persistent rumination leads to apprehension and feeling ‘on edge’ for the majority of the time (DSM-IV). In addition, the psychological distress experienced when we worry is significant, with recent research showing a link between psychological distress and rumination (Morrison and O’Connor 2005).

Worry content has been shown to vary with age, marital status, education and gender (Lindesay *et al.* 2006). Individuals with ID may have distinct negative experiences that influence the nature of their worries, for example, people with ID are likely to be subjected to stigmatised treatment (Dagnan and Jahoda 2006). Moreover, they may experience social exclusion and have difficulties forming social relationships with peers from an early age (La Greca 1981). Throughout the lifespan individuals with mild ID are aware of such negative treatment and can recount experiences of stigma, and report lack of perceived social acceptance (Jahoda *et al.* 2008). These experiences have been linked to the

development of low self-esteem and feelings of hopelessness in people with ID (Dagnan and Sandhu 1999).

Zigler *et al.* (2002), have also indicated how early childhood experience may play a role in the personality development of individuals with ID. In particular, they propose that these children's cognitive difficulties are likely to lead to experience of frequent failure. In turn, this may lead to reluctance to try new tasks, low self-image, lack of goal setting and increased learned helplessness (Zigler and Balla 1982). Zigler *et al.* (2002) have carried out experimental studies showing that children with ID have a lower 'expectancy of success' than typically developing children (Gruen and Zigler 1968). It is also important to take account of contrasting findings which demonstrate the resilience of people with ID. Cooney *et al.* (2006) found that young people with mild ID left school feeling as confident as their mainstream peers about achieving their future goals.

The transition from school/college into adulthood is an important time to examine the content and salience of worries in individuals with a mild ID. Transition can be a particularly stressful and worrying time for *all* adolescents when they seek to develop their own identity in relation to others (Eccles *et al.* 1995). During this time they may become aware of what choices life offers them, such as identifying where they might live and future occupation (Cameron and Murphy 2002). Wehmeyer and Palmer (2002) found that students who reported a greater sense of self-determination achieved better outcomes in employment, independent living, financial independence and access to health resources. People's particular past experience and resultant sense of self-efficacy could be predicted to be related to the nature of their worries at this stage of transition. It is of interest to explore the content and salience of worries of people with a mild ID, at a stage when they consider

their future and place in the ‘social world’. To explore the content and salience of worries in people with intellectual disabilities requires an approach which helps people to express their thoughts and feelings, rather than measures which place too many cognitive demands on participants. Research also shows that when measures used are salient, this can be an effective way of tapping into peoples cognitions (Laing 1988).

Research Aims

This exploratory study aimed to compare the worries experienced by young people with and without mild ID at the stage of transition from college to adulthood.

Research Questions

Are there differences *between groups* of young people with and without a mild ID at the stage of transition from college to adulthood in terms of:

- The worries both groups describe.
- The salience of these worries regarding 1) level of rumination and 2) level of distress they cause.
- Level of reported self-efficacy.
- Level of reported anxiety.

The study also explored whether there were *within group* correlations between rumination, distress, self-efficacy, and anxiety.

Methods

Participants and recruitment: Twenty six participants with ID and twenty six typically developing young people were recruited from a Further Education (FE) college in Glasgow. The two groups were as closely matched as possible in terms of gender, age, socio-demographic status, and stage of transition. Classes of potential participants were identified by the researcher through using criteria from the Adaptive Behaviour Scale (ABS-RC: 2, Nihira, 1993) by ascertaining whether they could 1) talk to others about sports, family, group activities etc, 2) sometimes use complex sentences containing ‘because’, ‘but’ etc., and 3) answer simple questions such as ‘What is your name?’ or ‘What are you doing?’. Both groups were recruited at the stage of finishing a college course with six months remaining. Informed consent was obtained from all participants who decided to proceed (Appendix B). Details of participant characteristics are shown in table 1.

[Insert table 1 about here]

Materials

Materials are outlined in the order in which they were presented to participants. Firstly, background information was obtained from each participant to ascertain socio-economic status, age, gender, and stage of transition. Socio-economic status was determined by participant’s postcodes using the Carstairs Index (Carstairs 1991). The semi-structured interview and self-report materials concerning anxiety and self-efficacy were then carried out to obtain participants’ thoughts and feelings. The Wechsler Abbreviated Scale of Intelligence - III (WASI-III) was carried out last because it has right and wrong answers, which is contrary to the spirit of the other measures.

Semi-structured ‘worry’ interview

The aim of this exploratory component was to establish a dialogue about these young people's worries, as experts in their own lives, and to ask them to identify their four most salient worries. On the basis of previous quantitative work concerning themes of adolescent worry (Kaufman *et al.* 1993; Miller and Gallagher 1996), a series of twelve photographs depicting these themes were piloted on 6 individuals with a mild intellectual disability and the most salient pictures were selected for the present study (Appendix C). This piloting helped ensure that the materials, wording, and procedures were comprehensible to participants with an intellectual disability to help them to identify their worries.

Photographs were used as a means to open up dialogue on the twelve themes identified by Miller and Gallacher (1996) as key areas of worry for adolescents. Young people with ID may find it difficult to reflect on their thoughts and feelings in the abstract, and the aim of the photographs was to make this a more engaging process with the photographs providing a reference point for talking about their worries. Participants were shown each photograph and were first asked 'what is this a picture of?' and then what does this picture make you think of?' The views expressed by participants were recorded and transcribed verbatim.

Following the opportunity for discussion about each of the photographs, participants were asked to rate whether what they had discussed was something they currently worried about.

They were asked to place the each picture in one of two piles: either 1) 'yes, this is currently a worry for me,' or 2) 'no, this is not currently a worry for me.' When all of the photographs had been shown and discussed, they were asked to rank the pictures that they had placed in their 'yes' pile into their top 4 worries. They were then asked to rate each of these 4 worries in terms of rumination (how much they currently worried about each of the top 4 worries) and distress (how thinking about each of these 4 worries made them feel).

Rating of rumination and distress was done using 3 point visual analogues, namely blocks increasing in size with the words, ‘sometimes a worry’, often a worry’, and ‘always a worry’. Responses were given a score from 1 to 3 with a 3 signifying ‘always worry’. Using visual analogue as a method of presentation has previously been used successfully in ID populations (e.g. Stigma Scale, Szivos 1991).

General Self-efficacy scale-12 (GSES-12) (Appendix C)

This scale was initially developed by Sherer *et al.* (1982) to measure self-efficacy. The original scale was refined to 12 items by Woodruff and Cashman (1993). The scale is divided into three sections which measure persistence, effort and initiative. Such scales have previously been used in ID populations (Payne and Jahoda 2004). This scale has good internal consistency ($\alpha=0.69$). The scale takes approximately 20 minutes to administer.

Glasgow Anxiety Scale-LD (Appendix C)

This 27 item scale developed by Mindham and Espie (2003) has good psychometric properties: test-retest reliability ($r=0.95$), good internal consistency ($\alpha=0.96$), and is reasonably correlated with Becks Anxiety Inventory ($p=0.75$). The scale takes approximately 5-10 minutes to administer.

Wechsler Abbreviated Scale of Intelligence

A formal measure of level of cognitive ability was conducted using the Wechsler Abbreviated Scale of Intelligence (WASI-III). This is an abbreviated version of the Wechsler Adult Intelligence Scale – III (WAIS -III; Wechsler 1997). The Vocabulary and Matrix Reasoning subscales were used in this study. Correlations between the WASI and

WAIS -111 are reasonable, at 0.88 for Vocabulary, 0.66 for Matrix Reasoning and 0.87 overall.

Justification of sample size

This was an exploratory investigation, however a power calculation based upon within group correlations was carried out. To achieve power of 0.80 at the 5% level of significance for a two-tailed correlation, it was calculated that the sample size required would be 52 (26 in each group).

Results

The first section of the results will outline the four main worries presented by the two groups, along with descriptive data. This will be followed by a comparison of the amount that both groups ruminate about their worries and the level of distress they report.

The second section will present the within group correlations between rumination and distress scores, and in turn, whether they are correlated with established measures of self-efficacy and anxiety (GSES-12 and GAS-LD). Further details of all analyses can be found in Appendix D.

1a) Worries

Each participant identified their 4 top worries and ranked them from 1 to 4, (4 = biggest worry). Worries were recorded verbatim, transcribed, content analysed and grouped accordingly under the twelve topic areas. A second independent rater was asked to group the participants' responses into the categories developed for the twelve topic areas and the inter-rater agreement obtained was 100%. Rankings for worry categories were summed.

Figure 1 shows that the sums of ratings of the top 4 worries of people with an intellectual disability were different to those without intellectual disability, apart from ‘failing’ which featured as one of the top 4 worries in both groups.

[Insert figure 1 about here]

Participants with intellectual disabilities

The greatest worry within the intellectual disability group was about being bullied, followed by worry about close friends and family members dying, failing in life, and worries about making and keeping friends. Table 2 shows examples of the most common content of the top 4 worries in this group.

[Insert table 2 about here]

Bullying: Table 2 shows that the worries of the young people with intellectual disabilities regarding bullying tended to reflect their recall of past experience. Although only a minority of these participants reported still experiencing bullying they worried about it happening again in the future.

Death and loss: The worries about death commonly reflected the fear of losing someone that the intellectually disabled person was close to. How the person would cope by themselves was a common concern.

Failure: Where participants in the intellectual disability group had rated fear of failure as one of their top worries, they tended to reflect past experiences of failing as evidence that they might fail again in the future.

Friendship: A common concern about friendships within the intellectual disability group was about making and keeping friends and the views expressed often reflected fears about this and about not fitting in with peers.

Non-Intellectually disabled group

Figure 1 shows that the greatest worry within the control group was worrying about not getting a job, followed by not having enough disposable income, worries about failing and worrying about the number of decisions they would have to make in the near future. Examples of the content of the top four worries of this group are shown in table 3.

[Insert table 3 about here]

Work: Worries about work in the non-disabled group often reflected fears about obtaining and keeping a job, the interview process, and how to integrate into the workplace.

Money: The views on money worries reflected more superficial concerns about material possessions and what they might not be able to afford.

Failure: Fear of failure concerned failing exams, driving tests and obtaining qualifications.

Decision Making: The worries about having to make decisions reflected concerns about the sheer volume of responsibility and decisions that many people within the non-disabled group felt overwhelmed by.

1b). Rumination and distress

In order to test the distribution of the data within the rumination, distress, GSES-12 and GAS-LD measures, the Kolmogorov- Smirnov test was employed. This indicated that all

data met assumptions of normality, and was further supported by visual interpretation of histograms of the data. Consequently, parametric analyses were used throughout.

Rumination

Participants' top four worries were rated for degree of rumination (where 1= sometimes, 2=often, 3 =always). Rumination scores for each participant's top 4 worries were totalled, giving a total rumination score out of a possible 12. Analysis indicated that the ID group scores ranged from 8.0 to 12.0, with a mean rumination score of 10.27 (SD = 1.04). In comparison, the rumination scores for the control group ranged from 4.0 to 12.0, with a mean rumination score of 9.11 (SD = 2.29).

An independent samples t-test was conducted to evaluate the difference in rumination scores between groups. Results indicated that there was a significant difference between groups on rumination scores [$t(34.95) = 2.34, p = 0.025$] with an effect size of 0.98.

Distress

Participants' top 4 worries were rated for degree of distress (where 1 = sometimes, 2=often and 3 = always). Distress scores for each participant's top 4 worries were totalled, giving a total rumination score out of a possible 12. Analysis indicated that ID group scores ranged from 6.0 to 12.0, with a mean distress score of 9.69 (SD = 1.89). In comparison, the distress scores for the control group ranged from 4.0 to 12.0, with a mean distress score of 6.88 (SD = 2.18).

An independent samples t-test was conducted to evaluate differences in distress scores between groups. Results indicated that there was a significant difference in distress scores between groups [$t(50) = 4.96, p = 0.000$] with an effect size of 0.3.

2) *Within group associations*

Rumination and distress

The association between rumination and distress scores was investigated using Pearson's Product-Moment Correlation coefficients. A strong positive correlation was found between distress and rumination scores within the intellectual disability group, [$r = 0.55, p = 0.004$], and a moderate significant correlation between distress and rumination scores within the control group, [$r = 0.43, p = 0.029$].

Rumination, distress and self-efficacy and anxiety

The association between rumination scores, distress scores and established measures of self-efficacy (GSES-12) and anxiety (GAS-LD) were investigated using Pearson's Product-Moment Correlation coefficients. In the intellectual disability group, a strongly significant positive correlation was found between distress scores and the GAS-LD, [$r = 0.76, p = 0.000$]. Ruminations scores were not found to be correlated with either the GSES, [$r = 0.15, p = 0.468$], or the GAS-LD, [$r = 0.27, p = 0.189$].

For the non-disabled group, a significant positive correlation was found between distress scores and the GAS-LD, [$r = 0.84, p = 0.000$] and between rumination scores and the GAS-LD, [$r = 0.52, p = 0.006$]. Rumination scores were not found to be correlated

with the GSES-12, [$r = -0.25$, $p = 0.221$], and distress was not correlated with GSES-12 scores [$r = 0.17$, $p = 0.405$].

3) *Further analysis of self-efficacy subscales and anxiety*

Of the three subscales of the GSES-12 (initiative, effort, and persistence), results indicated a strong positive correlation between the Glasgow Anxiety Scale scores and the General self-efficacy persistence subscale score (GSES-12), [$r=0.62$, $p = 0.001$] for the ID group and a moderate positive correlation for the control group, [$r=0.48$, $p = 0.013$]. There was a medium negative correlation between anxiety scale scores and GSES-12 effort scores but only for the control group [$r = -0.4$, $p = 0.044$]. There was no correlation between the GSES-12 initiative subscale and GAS-LD for either group.

Scores between groups

An independent samples t-test showed a significant difference between the control group and ID group on GSES-12 total scores [$t(50) = 2.79$, $p=0.008$]. The mean GSES-12 total score was 37.19 (SD 4.29) for the ID group and 33.81 (SD = 4.46) for the control group. The self-efficacy scoring ranged from 1=strongly disagree to 5=strongly agree and therefore the ID group scores indicated they were significantly less self-efficacious than controls.

Analysis of the three subscales indicated the ID and control groups were not significantly different on the initiative subscale, [$t(50) = 1.130$, $p = 0.264$] or the effort subscale, [$t(50) = -0.169$, $p=0.866$]. However, a significant difference was found between groups on persistence subscale scores, [$t(50) = 3.316$, $p=0.002$] with an effect size of 0.18.

A significant difference was found between groups on the Glasgow Anxiety Scale, [$t(50) = 2.247, p = 0.029$].

Discussion

The results showed that the worries of both of these groups are qualitatively different at this stage of transition. The most frequently expressed worry for participants with an intellectual disability was related to being bullied, losing someone they are dependent upon, failing in life, followed by making and keeping friends. The most frequent worries of typically developing young people at this time point were found to be getting a job, followed by not having enough surplus money, failing, and having to make decisions about their future choices. Not only was there a difference in the nature of worries expressed, but there was also a significant difference in the intellectual disability group in that they also ruminated more about their worries and were more distressed. This study also examined whether there were within group differences in levels of anxiety and in sense of self-efficacy. A strong positive correlation was found between the GAS-LD and the General Self-efficacy scale for the intellectual disability group, but only on the persistence subscale. Examination of within group correlations between the GAS-LD and distress ratings showed the GAS-LD was correlated with distress for both groups. Rumination scores were correlated with the GAS-LD for the control group but not for the intellectual disability group. Additionally, we examined between group differences of anxiety and self-efficacy. Results showed that people with an intellectual disability were significantly less self-efficacious than controls. A significant difference was also found between groups on the persistence subscale of the self-efficacy measure.

These findings do suggest that people with mild/moderate intellectual disabilities have distinct experiences that influence the nature of their worries, since people with intellectual disabilities frequently recalled experiences of feeling stigmatised and bullied in their childhood. Although only a small proportion reported *still* being bullied, most reported worrying about the possibility of it happening again, now or at some point in the future. It is known that many people with intellectual disabilities report past experiences of feeling stigmatised (Dagnan and Jahoda 2006) and results from this study suggest that such experience may continue to affect the types of things that people with intellectual disabilities worry about at a vulnerable time in their life. The finding that one of the biggest worries within the intellectual disability group is about failing in life is in keeping with the work of Zigler *et al.* (2002), who postulate that early childhood experience plays a role in the personality development of individuals with ID, and that children's cognitive difficulties are likely to lead to experience of frequent failure (Zigler *et al.* 2002). Also in keeping with this work is the finding that people with an intellectual disability felt significantly less self-efficacious than the non-disabled group, as this supports the idea that experience of failure leads to reluctance to try new tasks, have low self-image, self-determination, learned helplessness, and lower 'expectancy of success' (Gruen and Zigler 1968; Zigler and Balla 1982). It is interesting to note that one of the main worries in the non-disabled group was also about failing, although the content of worries related to failing within this category differed. The non-disabled group worried about failing specific events such as exams or driving tests, while the intellectual disability group expressed more global worries about being a failure and never making anything of their lives.

There were also marked differences in the worry content of both groups in relation to worries about death/dying. Within the non-disabled group the majority of worries were about their own mortality, whereas the intellectual disability group were all fearful about losing someone they are dependent upon. This worry about losing significant others in their lives may reflect their dependency upon family as well as the fact that they have limited social networks.

The finding that this group ruminate more and get more distressed about their worries may also have implications for their future mental health. It is known that people with intellectual disabilities are at risk of developing mental health problems (Einfeld and Tonge 1996), which may be linked to their experience of frequent failure and poor sense of self. Therefore, it may be important to identify ways to resolve these young peoples' worries or to give them the resources to deal with these worries, so that effects may be ameliorated. For example, increased self-determination may be one route to improving their resilience (Wehmeyer and Palmer 2002).

One of the key strengths of the present study is the careful piloting of the photographic materials to ensure the materials were salient to the population. The fact that these materials were used so successfully with both the intellectual disability group and the typically developing group shows their internal consistency, and also suggests that these materials allowed the participants to express their specific worries and the more general distress associated with these thoughts. A further strength of this study is that GAS-LD measure was used successfully in both groups, indicating its validity. Furthermore, a high degree of

consistency was found between the GAS-LD and rumination and distress scores, indicating this measure is a useful means of picking up anxieties in relation to worry.

Most importantly, the qualitative aspect of this research allowed us to gain insight into the real experiences and worries of young adults with mild/moderate intellectual disabilities as they make the transition to adulthood, thus providing a much richer understanding of concerns for young people around this difficult time.

Limitations

The present study did not consider the effects of age, gender, or socio-economic status on worry, and this would be an interesting area for further study in future research.

Additionally, this study took place at a single time point in transition, and despite providing useful insight into the nature of worries at this stage, we are unable to conclude whether the types of worries expressed changes as the young person goes through the transition process. Therefore, an important area for future research would be to examine whether these worries persist. It may be that worries remain the same but cause less distress once these young adults leave college, or it may be that concerns change as people actually have to deal with the situations they fear. For example, the biggest worry of the control group was related to jobs, and this may be likely to change as people obtain employment. A longitudinal study would hope to answer such questions, as well as investigating whether increased worry results in greater vulnerability to future mental health problems.

Despite these limitations this initial exploratory investigation provides us with a good grounding for further much needed research in this area. The study found that the intellectual disability group were more anxious, more distressed, and ruminated more than the non-disabled group, and also provides initial evidence that worries *may* be related to the experience of having an ID.

Research and Clinical Implications

This research provides a starting point for examining the worries of young people with mild/moderate ID at the stage of transition to adulthood. The materials and approach used in this study could also have direct clinical utility, and could be used to explore the worries that young people with mild/moderate ID have, but may find difficult to express. The worry themes elicited and views expressed within this study may also be a useful starting point for the development of a measure for worry for this population, and further research could work towards the development of such a tool. Even though this was an exploratory study, the particular worries that the young people expressed have implications for services who could be involved in preventative work to reduce worry, rumination and distress, and help increase resilience. For example, an educational package could be designed for services to address the particular worries of college leavers with intellectual disabilities as part of such a preventative model. Additionally, greater understanding of the concerns of this population at transition may facilitate guidance opportunities within schools and colleges and thus help identify appropriate support. Furthermore, these findings may be of use to clinicians as worries may be predictors of emotional distress.

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Table 1: Participant characteristics expressed as percentage, mean, SD and range.

Patient characteristic/ demographic information	Intellectual disability group (n=26)	Non-intellectual disability group (n = 26)	Total group (n = 52)
Age (mean, SD, range)	Mean = 18.23; SD = 0.82; range = 3 (min=17, max=20)	Mean = 18.07; SD = 0.845, range = 3 (min=17, max=20)	Mean 18.16, SD = 0.83, range =3 (min17 max 20)

Gender (n, %)					
Male	16 (61.5%)		15 (58%)		31 (60%)
Female	10 (38.5%)		11 (42%)		21 (40%)
Ethnicity (white)	26 (100%)		26 (100%)		52 100%
Estimated IQ score (mean, SD, range)	Mean = 63.30; SD = 3.10; Range = 11 (min=58, max=69)		Mean = 97.38; SD = 6.19 Range = 23 (min=87,max=110)		
Deprivation category (n, %) 1(most affluent) to 7 (most deprived) Mean (SD), range	<u>Depcat score</u>	<u>No. of subjects (%)</u>	<u>Depcat score</u>	<u>No. of subjects (%)</u>	<u>Total group</u>
	1	0 (0)	1	0 (0)	Mean: 5.27; SD 1.31
	2	0 (0)	2	0 (0)	Range: 4
	3	4 (15.38)	3	4 (15.38)	(min3 max 7)
	4	4 (15.38)	4	5 (19.23)	
	5	1 (3.85)	5	1 (3.85)	
	6	14 (53.85)	6	13 (50)	
	7	3 (11.54)	7	3 (11.54)	
	Total = 26 100%		Total = 26 100%		

Table 2: Examples of quotations concerning intellectually disabled participants 4 highest rated worries.

Bullying: answers reflected people remembering their past experience of bullying; although not many reported current bullying they worried that it could happen in the future because of past experience.	<i>'I was bullied at school. It makes me feel like I'm useless. Just cause I don't feel the need to cry anymore about it doesn't mean it's not on my mind' 'I feel I should give up, that's the way I feel'</i>
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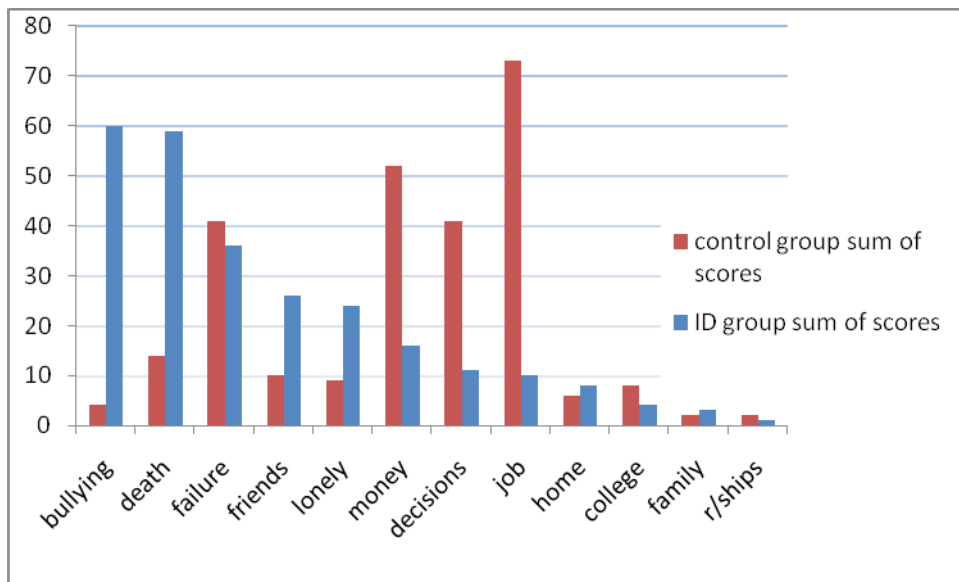
<p><i>'I've never been bullied here (college) but it's crossed my mind quite a few times that I could be picked on.' Because I'm a bit slower, like'</i></p> <p><i>'I worry about it, but in college or work you don't get it so much 'cause it's older and a wee bit more mature, but you still get it, just not as much, just not as much as school, I got it then'.</i></p>	<p><i>'It's scary. I never get bullied at college, but at school. I still think about it. Still look over my 'shoulder'</i></p> <p><i>'I was bullied at school. I worry about getting bullied here. I hav'nae been but it could happen. What if I get bullied at work? Who will I tell? 'worried in case I get battered'</i></p>
<p>Death/losing someone important to the person: answers reflected worrying about losing someone that the person with an ID is dependent upon.</p> <p><i>'I was really upset about it. I usually get told things last, like when someone dies or something. I get told things last all the time. I think they were trying to protect me so I didn't get upset that time. I was a bit angry 'cause he was my grandpa'</i></p>	<p><i>'If I lost my family that would be terrible to me. A worry, if they weren't here with me'</i></p> <p><i>'I think it's worrying because what if it's your mum or you dad that dies and you'd feel really lonely? I don't like thinking about it'. 'Who would I live with?'</i></p> <p><i>'my grandpa died and he used to help me make decisions. Who will help me now?'</i></p>
<p>Failure: answers reflected drawing on past experiences of failing as evidence they might fail again in the future.</p>	<p><i>'I feel like a failure all the time. it's just like the useless thing again in a way, because I can't get college right, I can't get friends right... I want to join clubs but it's like friends, are they going to judge me for how I am? So it's the same kind of roller coaster up here and down there, will I fail?'</i></p>
<p>Friends: answers reflected worrying about not fitting in, making and keeping friends.</p>	<p><i>'I have to try real hard to get on with people' 'I have some friends but I hardly see them, but when they don't text me I get kind of worried about them in case they don't want to be my friend, and when I leave college they might not text me anymore'</i></p>

Table 3: Examples of quotations concerning control group participants 4 highest rated worries.

<p>Work: Worries about work in the non-disabled group often reflected fears about obtaining and keeping a job, the interview process, and how to integrate into the workplace.</p>	<p><i>'I'm finding it quite hard to get a job just now. It's a worry. I've filled in six applications but I've not heard back from any of them.' 'It's on my mind a lot of the time' 'I won't like meeting new people at the start, just 'cause they are all older guys and that, and I will'nae really have</i></p>
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	<i>anything in common with them'</i>
Money: The views on money worries reflected more superficial concerns about material possessions and what they might not be able to afford.	<i>'I'd be concerned to make sure I have money for new trainers, some music'. It bothers me whether I have money to spend on clothes or not.'</i>
Failing: Fear of failure concerned failing exams, driving tests and obtaining qualifications.	<i>'the school said I should just leave, 'cause it wasn't like I was going to get my higher anyhow. I felt like a failure, I still do. I'll never pass these exams.'</i> <i>'I've got my driving test this afternoon, and this'll be my third time. I'm really nervous about failing it again'</i>
Decisions: The narrative on worries about having to make decisions reflected concerns about the sheer volume of responsibility and decisions that many people within the non-disabled group felt overwhelmed by.	<i>'I feel as if I've got loads of decisions to make just now, like I'm doing driving lessons just now and I'm ready to sit my test once I've done my theory, but I need to think about money for the test and when to sit it and I'm still trying to study for it at the same time as doing all my college stuff, so that's on my mind. Too many decisions.'</i>

Figure 1: Worries of young people as they make the transition to adulthood.



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Appendix B: Participant Information sheet presented visually and verbally Research

Participant Information Sheet

The nature of worries experienced by young people as they make the transition to adulthood

I am a researcher who is interested in **what people worry about as they are about to leave school or college**. I am interested in speaking to people aged between 16 and 22 years to find out more about people's experience of what worries them.

What this study is about: This study is about understanding the types of things people worry about as they leave school or college. This is important because if we can understand more about the types of things people in this age group worry about it will help schools and colleges know what kinds of support should be in place to help people as they make this step (transition).

What is involved? I would ask to meet you for around 40 minutes at your school/college to enquire about the types of things you commonly worry about. If you find this is too long I could come back to finish the interview, with your consent. There are no right and wrong answers. If you give me consent I will record the interview.

If you are interested in taking part... If you would like to take part please complete the tear-off slip below and return it to me or your class teacher in the stamped addressed envelope provided. Your teacher will have a box labelled 'Research study tear off slips'. Thank you for reading this information sheet and I do hope I have the chance to find out more about your experiences of worry. Please complete the tear-off slip if you are happy to be contacted by me.

Marisa Forte: Trainee Clinical Psychologist (address and contact number)

Signature

Name

Address

Telephone (optional) *For office use: The nature of worries experienced by young people as they make the transition to adulthood. Please contact Marisa Forte, Trainee Clinical Psychologist, contact number*



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Appendix B: Consent form presented visually and verbally to control group

Consent Form

Title of Project: The nature of worries experienced by young people as they make the transition to adulthood.

Please initial box

I confirm that I have read and I understand this participant information sheet for the above study highlighted in bold and that I have been given the opportunity to ask any questions relating to the study.

☐

I understand that I am under no obligation to participate in this study. It is entirely voluntary and I can withdraw at any time, without giving a reason and that this will not affect any aspect of my care

☐

I am aware that the interview will be recorded by the researcher, Marisa Forte, and only used for the purposes of the research study, as described in the participation information sheet.

☐

I am aware and understand that the researcher, Marisa Forte, may publish direct quotations said by me during the interview.

☐

I understand that all names, places and anything that could identify me will be removed and nothing that identifies me will appear for others to see.

☐

I agree to take part in the above study (date)

Signature of participant:

Name of participant/ID number

Name/signature of researcher:

☐



CONSENT FORM

Please Circle: YES NO



Have you read the information sheet?

✓

x



Have you had chance to ask questions?

✓

x



Do you want to take part in my study?

✓

x



Appendix C

Copy of the General Self efficacy Scale-12 (GSES-12: Sherer et al, 1982)

Initiative items

- 1) If something looks too complicated, I will not even bother to try it
- 2) I avoid trying to learn new things when they look too difficult.
- 3) When trying something new, I soon give up if I am not initially successful.

Effort items

- 4) When I make plans, I am certain I can make them work.
- 5) If I can't do a job the first time I keep on trying until I can.
- 6) When I have something unpleasant to do, I stick to it until I finish it.
- 7) When I decide to do something, I go right to work on it.
- 8) Failure just makes me try harder.

Persistence items

- 9) When I start important goals for myself, I rarely achieve them.
- 10) I do not seem to be capable of dealing with most problems that come up in my life.
- 11) When unexpected problems occur, I don't handle them very well.

12) I feel insecure about my ability to do things.

Appendix C

Glasgow Anxiety Scale-LD

Glasgow Anxiety Scale for people with Intellectual Disabilities

Each item scored as: (A) 'never'; (A) 'sometimes'; and (A) 'always'.

Question Score

- 1 Do you worry a lot? (...*feel worked up/wound up/uptight/up to high doh*)
- 2 Do you have lots of thoughts that go round in your head? (...*thoughts that you can't stop/come from nowhere*)
- 3 Do you worry about your parents/family?
- 4 Do you worry about what will happen in the future? (*tailored to the individual; e.g. What will happen if you can't live with your mum anymore?*)
- 5 Do you worry that something awful might happen?
- 6 Do you worry if you do not feel well? (...*if you feel sick*)
- 7 Do you worry when you are doing something new? (...*like for the first time*)
- 8 Do you worry about what you are doing tomorrow?
- 9 Can you stop worrying? (reverse score)
- 10 Do you worry about death/dying?
- 11 Do you get scared in the dark? (...*think of being in bed with the lights out: Would you be scared?*)
- 12 Do you feel scared if you are high up? (...*think of being up a high building...*)
- 13 Do you feel scared in lifts or escalators? (*Would you go in?*)
- 14 Are you scared of dogs? (*Would you stroke/clap?*)
- 15 Are you scared of spiders? (*Would you go near?*)
- 16 Do you feel scared going to see the doctor or dentist?
- 17 Do you feel scared meeting new people?
- 18 Do you feel scared in busy places? (...*like crowds, shopping centre*)
- 19 Do you feel scared in wide open spaces? (...*nothing round about you*)
- 20 Do you ever feel very hot or sweaty? (...*all hot and bothered*)
- 21 Does your heart beat faster?
- 22 Do your hands and legs shake?
- 23 Does your stomach ever feel funny, like butterflies?
- 24 Do you ever feel breathless? (...*hard to breathe/out of breath*)
- 25 Do you feel like you need to go to the toilet more than usual? (...*for a 'pee'*)
- 26 Is it difficult to sit still? (...*feel you can't sit at peace*)
- 27 Do you feel panicky? (...*get into a panic/a 'state'*)

Appendix C: Examples of photographs, taken by the author, presented to each participant to stimulate dialogue on worries.

DECISION MAKING



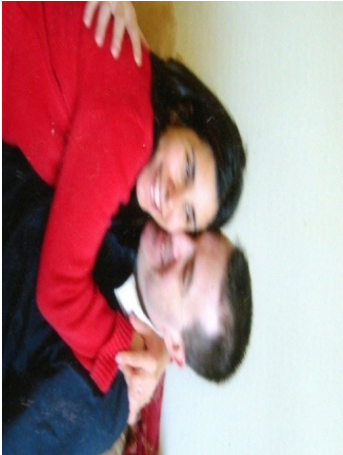
WORK



FAMILIES



RELATIONSHIPS



Appendix C

MONEY



HOME



Appendix D

Content analysis of the intellectual disability group's top 4 worries:

Most common themes in:

Worries about bullying

% of people who mentioned the following:

Worries that previous experience of bullying will happen again	46%
Worries in case people make fun of me for being 'different'	23%
Worries in case I am bullied and cannot stand up for myself	13%
Worries about not being able to say no when I do not want to do something	7%

Worries about death/dependency

People close to me dying	44%
Worries about what will happen to me in the future (when family are not here)	35%
Worrying about someone close to me becoming very ill	37%
Whether I will be able to live by myself when I am older/without family	27%

Worries about failing

Not making anything out of my life	35%
Not having enough confidence in myself	27%

Worries about friendship

Friends not really liking me /difficulty making friends	38%
Not being able to trust friends	27%
Not managing to keep in touch with friends	13%
Falling out with close friends	7%

**Independent Inter-rater agreement of content in both groups was 100 %.*

Content analysis of the control group's top 4 worries

% of people in non ID group

Worries about work

Worries about money

Worries about failure

Worries about making decisions

Having too many decisions to make	29%
Worries because I can't make decisions/unable to solve problems	21%
Worries about leaving home, friends, family	15%

Worries because other people are trying to make decisions for me

13%

Appendix D

Group statistics for GSES-12 total scores, subscale scores, and GAS-Id scores

Group membership		gender	N	Mean	SD	Std. Error Mean
ID	GSES total score	Male	16	37.31	4.175	1.044
		Female	10	37.00	4.714	1.491
	GSES initiative	Male	16	7.63	2.062	.515
		Female	10	6.90	2.025	.640
	GSES effort	Male	16	17.88	3.243	.811
		Female	10	17.20	3.736	1.181
	GSES persistence	Male	16	11.75	2.955	.739
		Female	10	12.90	3.107	.983
	Glasgow Anxiety Scale (GAS-Id)	Male	16	23.06	6.875	1.719
		Female	10	25.60	8.113	2.566
control	GSES total score	Male	15	32.60	3.247	.838
		Female	11	35.45	5.466	1.648
	GSES initiative	Male	15	5.93	2.251	.581
		Female	11	7.36	3.802	1.146
	GSES effort	Male	15	17.93	2.576	.665
		Female	11	17.55	3.984	1.201
	GSES persistence	Male	15	8.73	2.404	.621
		Female	11	10.55	3.174	.957
	Glasgow Anxiety Scale (GAS-Id)	Male	15	15.60	6.243	1.612
		Female	11	23.73	9.551	2.880

*higher scores = low self-efficacy

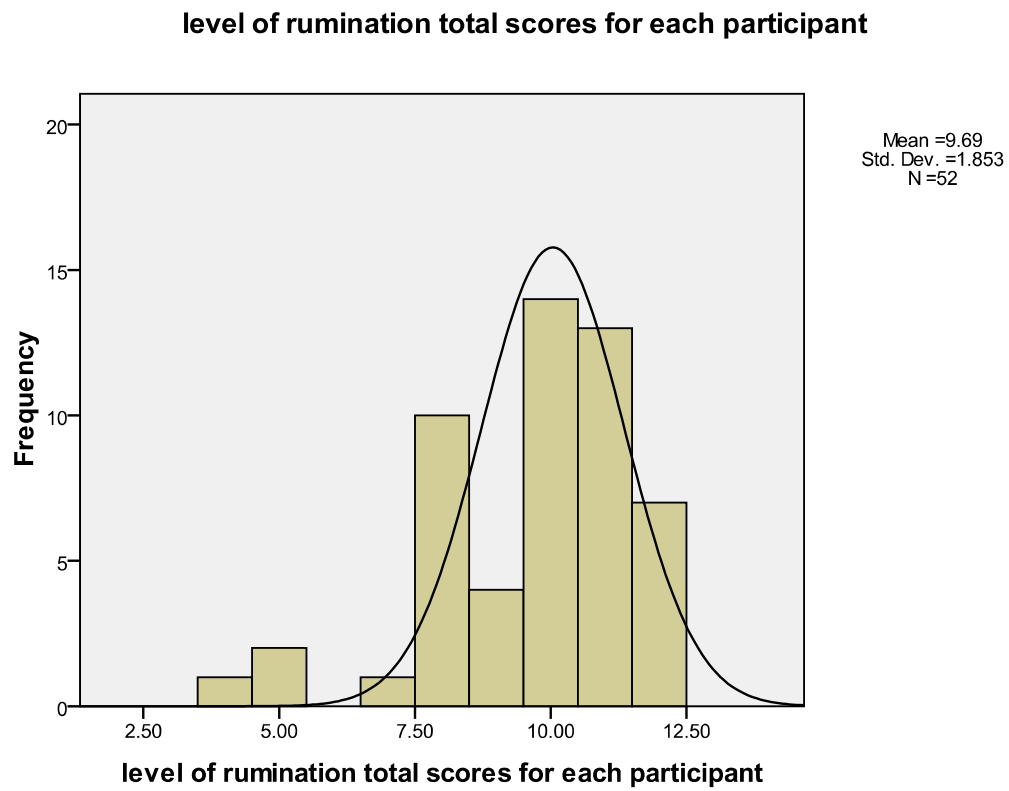
Appendix D

One-sample Kolmogorov-Smirnov Test

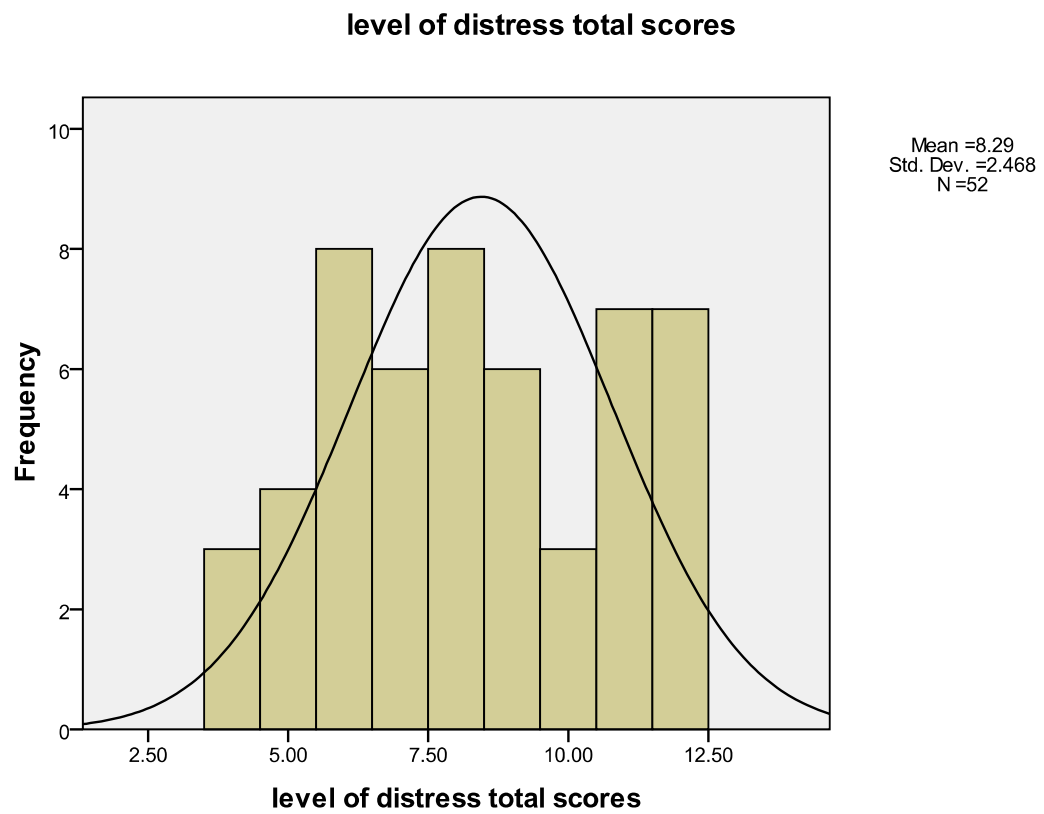
	Level of rumination total scores for each ID participant (max=12)	Level of rumination total scores for each control participant (max=12)	Level of distress total score for each ID participant (max=12)	Level of distress total score for each control participant (max=12)	GSES total score for each ID participant	GSES total score for each control participant	GAS-Id total score for each ID participant	GAS-Id total score for each control participant
N	26	26	26	26	26	26	26	26
Normal Parameters ^a								
Mean ^b	10.2692	9.1154	9.6923	6.8846	37.1923	33.8077	24.0385	19.0385
Std. Deviation	1.0414	2.28608	1.89250	2.17857	4.29902	4.46336	7.32383	8.66478
Most extreme differences								
Absolute	.220	.159	.178	.196	.099	.196	.160	.103
Positive	.165	.149	.122	.196	.095	.196	.094	.103
Negative	-.220	-.159	-.178	-.093	-.099	-.120	-.160	-.099
Kolmogorov-Smirnov Z	1.122	.811	.909	1.000	.505	.998	.814	.524
Asymp. Sig (2-tailed)	0.161	.527	.380	.270	.961	.272	.552	.947

Appendix D

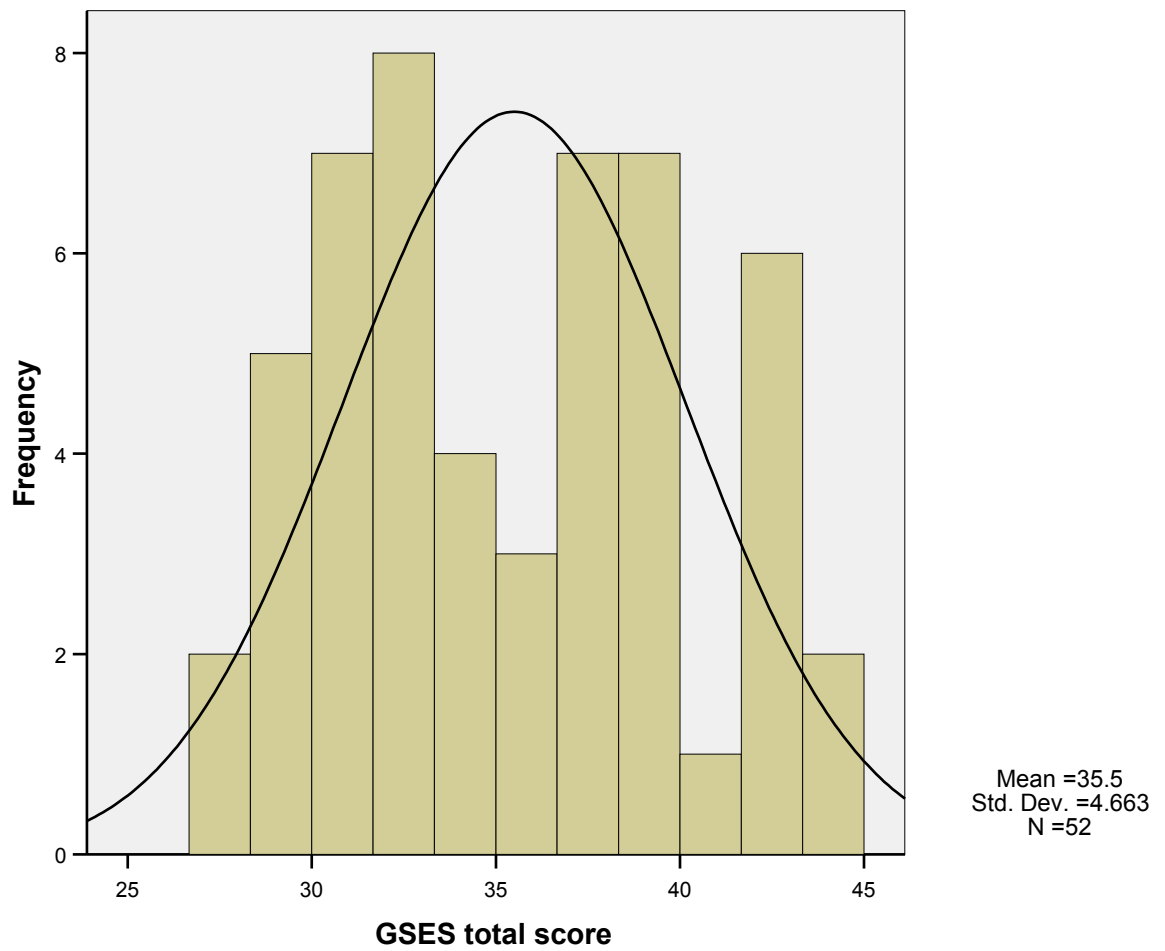
Histogram depicting total distribution of rumination scores (both groups).



Histogram depicting total distribution of distress scores (both groups).

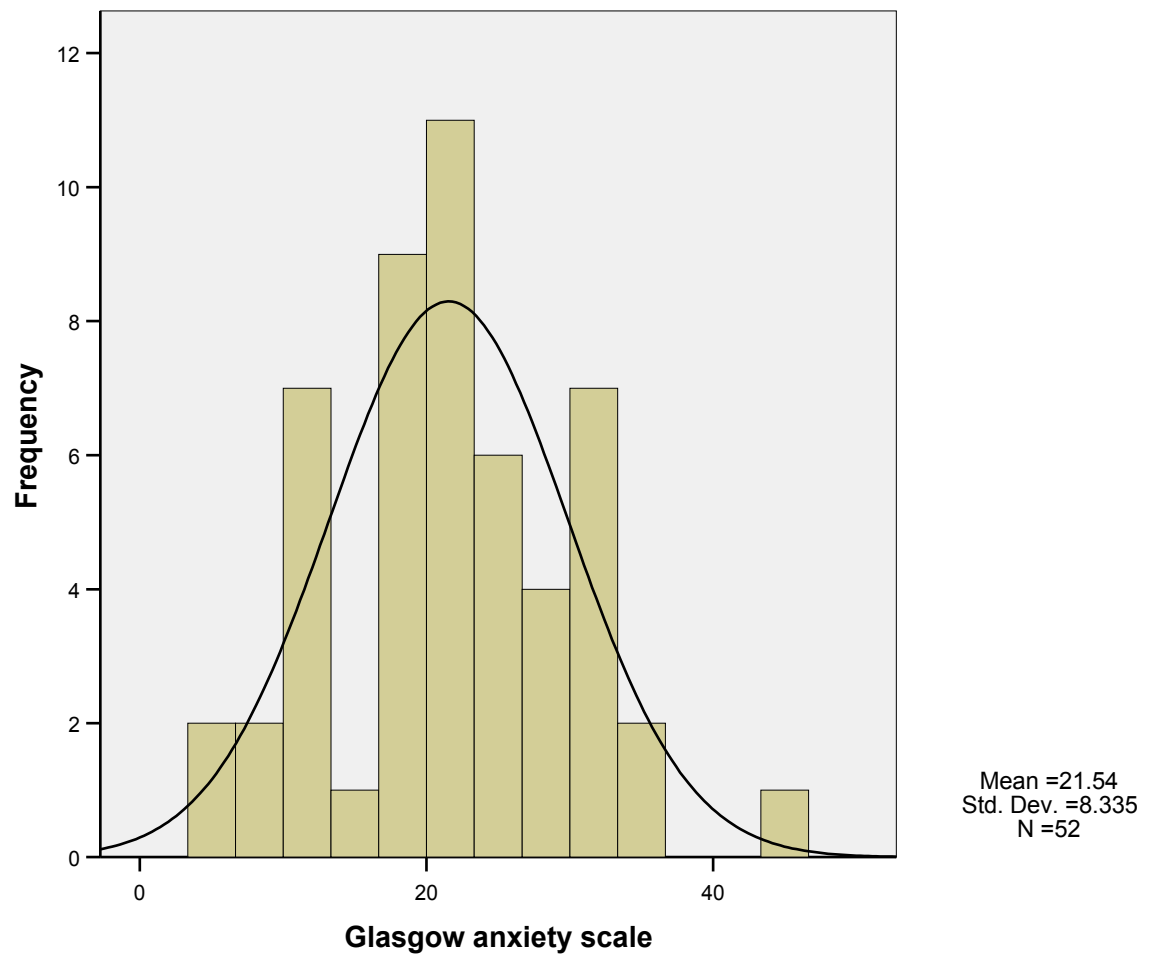


Histogram depicting distribution of scores on the GSES-12 (both groups).



Appendix D

Histogram depicting distribution of scores on the GAS-1d (both groups).



Appendix D

Independent samples t-test of difference in rumination scores between groups.

		Levene's test for equality of variances		t-test for equality of means					95% confidence interval of the difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean difference	Std. error difference	lower	upper
Level of rumination total scores for each participant	equal variances assumed	15.240	.000	2.342	50	.023	1.15385	.49267	.16429	2.14340
	equal variances not assumed			2.342	34.948	.025	1.15385	.49267	.15362	2.15407

Appendix D

Independent samples t-test of difference in distress scores between groups.

		Levene's test for equality of variances		t-test for equality of means					95% confidence interval of the difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean difference	Std. error difference	lower	upper
Level of distress total scores for each participant	equal variances assumed	.073	.788	4.961	50	.000	2.80769	.56595	1.6709	3.94443
	equal variances not assumed			4.961	49.041	.000	2.80769	.56595	1.6704	3.94498

Appendix D

Independent samples t-test of differences in GSES-12 totals, subscales, and GAS-Id between groups.

		Levene's test for equality of variances		t-test for equality of means		Sig. (2-tailed)	Mean difference	Std. error difference	95% confidence interval of the difference	
		F	Sig.	t	df				lower	upper
GSES total score	equal variances assumed	.057	.813	2.785	50	.008	3.385	1.215	.944	5.826
	equal variances not assumed			2.785	49.930	.008	3.385	1.215	.943	5.826
GSES initiative	equal variances assumed	4.435	.040	1.130	50	.264	.808	.715	-.629	2.244
	equal variances not assumed			1.130	43.840	.265	.808	.715	-.634	2.249
GSES effort	equal variances assumed	.153	.697	-.169	50	.866	-.154	.910	-1.982	1.675
	equal variances not assumed			-.169	49.807	.866	-.154	.910	-1.983	1.675
GSES persistence	equal variances assumed	.053	.819	3.316	50	.002	2.692	.812	1.061	4.323
	equal variances not assumed			3.316	49.850	.002	2.692	.812	1.061	4.323
Glasgow anxiety scale-Id (GAS-Id)	equal variances assumed	.584	.448	2.247	50	.029	5.000	2.225	.531	9.469
	equal variances not assumed			2.247	48.650	.029	5.000	2.225	.528	9.472

Appendix D

Correlational analysis for the Intellectual Disability group:

Matrix indicating correlations between distress scores and GAS-Id ($r=0.763$), and between distress and rumination scores ($r=0.551$).

Correlations

		level of rumination total scores for each learning disabled participant (maximum 12)	GSES total score for each LD participant (maximum)	level of distress total score for each LD participant (maximum 12)	GASLD total score for each LD participant
level of rumination total scores for ID participant (maximum 12)	Pearson Correlation	1	.149	.551**	.266
	Sig. (2-tailed)		.468	.004	.189
	N	26	26	26	26
GSES total score for each ID participant (maximum)	Pearson Correlation	.149	1	.204	.359
	Sig. (2-tailed)	.468		.317	.071
	N	26	26	26	26
level of distress total score for each ID participant (maximum 12)	Pearson Correlation	.551**	.204	1	.763**
	Sig. (2-tailed)	.004	.317		.000
	N	26	26	26	26
GASLD total score for each ID participant	Pearson Correlation	.266	.359	.763**	1
	Sig. (2-tailed)	.189	.071	.000	
	N	26	26	26	26

** . Correlation is significant at the 0.01 level (2-tailed).

Appendix D Correlational analyses for the non-disabled group

Matrix indicating 1) correlations between distress scores and GAS-Id ($r=0.84$), 2) rumination and GAS-Id ($r=0.52$) and 3) between distress and rumination scores ($r=0.43$)

Correlations

		level of rumination total scores for each control participant (maximum 12)	level of distress total score for each control participant (maximum 12)	GSES total score for each control participant (maximum)	GASLD total score for each control participant
level of rumination total scores for each control participant (maximum 12)	Pearson Correlation Sig. (2-tailed)	1	.428* .029	-.249 .221	.523** .006
N		26	26	26	26
level of distress total score for each control participant (maximum 12)	Pearson Correlation Sig. (2-tailed)	.428* .029	1	.170 .405	.839** .000
N		26	26	26	26
GSES total score for each control participant (maximum)	Pearson Correlation Sig. (2-tailed)	-.249 .221	.170 .405	1	.101 .625
N		26	26	26	26
GASLD total score for each control participant	Pearson Correlation Sig. (2-tailed)	.523** .006	.839** .000	.101 .625	1
N		26	26	26	26

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Appendix D

Total sample correlations: rumination, distress, GSES-12 and GAS -LD

Correlations

		level of rumination total scores for each participant	level of distress total scores	GSES total score for every participant	GASLD total score for every participant
level of rumination total	Pearson Correlation	1	.526**	.009	.488**
scores for each	Sig. (2-tailed)		.000	.949	.000
participant	N	52	52	52	52
level of distress total	Pearson Correlation	.526**	1	.352*	.803**
scores	Sig. (2-tailed)	.000		.011	.000
	N	52	52	52	52
GSES total score for	Pearson Correlation	.009	.352*	1	.303*
every participant	Sig. (2-tailed)	.949	.011		.029
	N	52	52	52	52
GASLD total score for	Pearson Correlation	.488**	.803**	.303*	1
every participant	Sig. (2-tailed)	.000	.000	.029	
	N	52	52	52	52

*. Correlation is significant at the 0.05 level (2-tailed)

**. Correlation is significant at the 0.01 level (2-tailed).

Appendix D

Correlations between anxiety (GASD-1d) and GSES-12 for ID group and non-disabled group

Correlations

group membership			GSES total score	GSES initiative	GSES effort	GSES persistence	Glasgow anxiety scale
LD	GSES total score	Pearson Correlation	1	.476*	.478*	.563**	.359
		Sig. (2-tailed)		.014	.013	.003	.071
		N	26	26	26	26	26
	GSES initiative	Pearson Correlation	.476*	1	-.195	.230	.144
		Sig. (2-tailed)	.014		.341	.258	.484
		N	26	26	26	26	26
	GSES effort	Pearson Correlation	.478*	-.195	1	-.315	-.182
		Sig. (2-tailed)	.013	.341		.117	.374
		N	26	26	26	26	26
	GSES persistence	Pearson Correlation	.563**	.230	-.315	1	.624**
		Sig. (2-tailed)	.003	.258	.117		.001
		N	26	26	26	26	26
	Glasgow anxiety scale	Pearson Correlation	.359	.144	-.182	.624**	1
		Sig. (2-tailed)	.071	.484	.374	.001	
		N	26	26	26	26	26
control	GSES total score	Pearson Correlation	1	.699**	.287	.505**	.101
		Sig. (2-tailed)		.000	.155	.008	.625
		N	26	26	26	26	26
	GSES initiative	Pearson Correlation	.699**	1	-.211	.270	.115
		Sig. (2-tailed)	.000		.300	.183	.575
		N	26	26	26	26	26
	GSES effort	Pearson Correlation	.287	-.211	1	-.442*	-.398*
		Sig. (2-tailed)	.155	.300		.024	.044
		N	26	26	26	26	26
	GSES persistence	Pearson Correlation	.505**	.270	-.442*	1	.479*
		Sig. (2-tailed)	.008	.183	.024		.013
		N	26	26	26	26	26
	Glasgow anxiety scale	Pearson Correlation	.101	.115	-.398*	.479*	1
		Sig. (2-tailed)	.625	.575	.044	.013	
		N	26	26	26	26	26

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Appendix E

Major Research Project Proposal and Addendum

An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood.

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Abstract

The present study will explore the content and salience of worries experienced by young people with mild intellectual disabilities (ID) at the stage of transition from school/college to adulthood. The role of self-efficacy and anxiety in relation to worry will also be examined. *Participants:* Fifty-two participants will take part in this study, 26 with a mild ID and 26 typically developing young people, all aged between 16-22 years. Prior to the main study a pilot phase will be conducted (n=2 with a mild ID). Participants will be recruited from Further Education colleges/schools in Glasgow and Renfrewshire. Groups will be matched, as far as possible, in terms of age, gender, socio-demographic status, and stage of transition. *Methods:* Participants will complete an open-ended 'worry' interview, the General Self Efficacy Scale-12, a sub-section of the Arc Self-Determination Scale, and the Glasgow Anxiety Scale-LD. *Research questions:* This is an exploratory study examining the worries of young adults with mild ID at a specific transition stage. Of interest is whether there are differences between ID and non ID groups in terms of i) worries described, ii) salience of worries (rumination and distress), and iii) relationships between self-efficacy, anxiety, and worry within groups. *Data Analysis:* Qualitative data from open-ended interviews will be subjected to content analysis. Within group correlations between anxiety and self efficacy will be examined. *Practical Applications:* This exploratory study will provide an initial investigation into the nature of worries in young people with a mild ID at transition to adulthood, and will explore whether worries are associated with a sense of self-efficacy, and the experience of having an ID. This information will be useful clinically, as it may facilitate guidance opportunities.

Background

Although there is a large amount of literature concerning worry content in the general population (Borkovec *et al.* 1983; Craske *et al.* 1989) there has been little work on the content and salience of worries experienced by individuals with a mild intellectual disability (ID). Borkovec *et al.* (1983) conceptualised 'worries' as 'a chain of thoughts and images which are negatively affect laden and relatively uncontrollable'. To engage in 'normal' amounts of worrying is regarded as adaptive and positive, and is recognised as something that we all engage in to a greater or lesser degree (Wells 1995). For example, worrying can help us be attentive to threat, therefore reducing the 'unexpectedness of an aversive event by facilitating coping' (Mathews 1990). However, chronic and repeated worrying can be maladaptive, such as in Generalised Anxiety Disorder, where persistent rumination leads to apprehension and feeling 'on edge' for the majority of the time (DSM-IV). In addition, the psychological distress experienced when we worry is significant, with recent research showing a link between psychological distress and rumination (Morrison and O'Connor 2005).

Worry content has been shown to vary with age, marital status, education and gender (Lindesay *et al.* 2006). Individuals with ID may have distinct negative experiences that influence the nature of their worries, for example, people with an ID are likely to be subjected to stigmatised treatment (Dagnan and Jahoda 2006). More over, they may experience social exclusion and have difficulties forming social relationships with peers from an early age (La Greca 1981). Throughout the lifespan individuals with mild ID are aware of such negative treatment and can recount experiences of stigma, and report lack of perceived social acceptance (Jahoda *et al.* 2008). These experiences have been linked to

development of low self-esteem and feelings of hopelessness in people with ID (Dagnan and Sandhu 1999).

Zigler *et al.* (2002) have also indicated how early childhood experience may play a role in the personality development of individuals with ID. In particular, they propose that these children's cognitive difficulties are likely to lead to experience of frequent failure. In turn, this may lead to reluctance to try new tasks, low self-image, lack of goal setting and increased learned helplessness (Zigler and Balla 1982). Zigler *et al.* (2002) have carried out experimental studies showing that children with ID have a lower 'expectancy of success' than typically developing children (Gruen and Zigler 1968). It is also important to take account of contrasting findings which demonstrate the resilience of people with ID. Cooney *et al.* (2006) found that students with a mild ID who were in their final year of schooling felt as confident as their mainstream peers about achieving their future goals.

The transition from school/college into adulthood is an important time to examine the content and salience of worries in individuals with mild ID. Transition can be a particularly stressful and worrying time for *all* adolescents when they seek to develop their own identity in relation to others, (Eccles *et al.* 1995). During this time they may become aware of what choices life offers them, e.g. identifying where they might live and future occupation (Cameron and Murphy 2002). Wehmeyer and Palmer (2003) found that students who reported a greater sense of self-determination achieved better outcomes in employment, independent living, financial independence and access to health resources. People's particular past experience and resultant sense of self-efficacy could be predicted to be related to the nature of their worries at this stage of transition. It is of interest to explore the

content and salience of worries of people with a mild ID, at a stage when they consider their future and place in the ‘social world’.

AIMS AND OBJECTIVES This is an exploratory study which aims to compare the content and salience of worries, and anxiety and sense of self-efficacy in relation to these worries, which are experienced by young people with and without mild ID at the stage of transition from school/college to adulthood.

Research Questions

Are there differences *between groups* of young people with and without mild ID in terms of:

- a) the type of worries they describe
- b) the salience of these worries in terms of 1) level of rumination, 2) level of distress caused

Are there differences *within groups* in terms of:

- a) levels of anxiety in relation to these worries
- b) sense of self-efficacy in relation to these worries

DESIGN This will be an exploratory study using mainly qualitative methods. It will involve a between groups comparison of open ended questions, to examine the content and salience of worries in young people with a mild ID and non-disabled young people. A within groups correlation of self-efficacy, anxiety, and worry will also be conducted.

PLAN OF INVESTIGATION

Participants and recruitment: The main group will have mild ID (n=26) and the comparison group will be typically developing young people (n=26).

The two groups will be as closely matched as possible in terms of gender, age, socio-demographic status, and stage of transition. All participants will be recruited from schools and Further Education (FE) colleges. Good links with FE colleges are already established and previous Doctorate in Clinical Psychology students have recruited successfully from FE colleges in Glasgow and Renfrewshire. The researcher has also contacted the Local Education Authority (LEA) regarding recruitment in secondary schools, both in special education and mainstream schooling.

Inclusion Criteria All participants will be between 16 and 22 years old, and will have had experience of transition either within the preceding year or will expect to within the following year. The researcher and class teacher will determine suitable classes of potential participants with mild ID by using criteria from the Adaptive Behaviour Scale (ABS-RC: 2, Nihira 1993) by ascertaining whether they can 1) talk to others about sports, family, group activities etc, 2) sometimes use complex sentences containing ‘because’, ‘but’ etc., and 3) answer simple questions such as ‘What is your name?’ or ‘What are you doing?’

Exclusion Criteria Those with more significant ID who do not have sufficient receptive and expressive verbal ability will be excluded, since they may have difficulty completing the tasks. Individuals with a severe visual or hearing impairment, which might prevent them from engaging with the research materials will also be excluded along with those whose first language is not English.

Semi-structured/open ended interview and Measures to be used in the study (in order of presentation)

Semi-structured /open ended ‘worry’ interview

The aim of this exploratory component is to establish a dialogue about these young people’s worries, as experts in their own lives, and to motivate them to generate their four most salient worries. We will use pictures to stimulate dialogue about worries, before asking them to identify their four main worries and to post them in order of significance. They will then be asked to rate their worries in terms of

- i) how much they ruminate about them, and
- ii) how much distress they cause.

To stimulate dialogue, participants will be asked to respond with ‘yes’ or ‘no’ to whether each item presented (verbally and visually) is a source of worry to them. For (i), when participants respond ‘yes’, they will be asked how *much* of a worry it is to them.

Participants will be asked to rate degree of worry using 3 point visual analogues, namely blocks increasing in size with the words, ‘sometimes a worry’, often a worry’, and ‘always a worry’. Responses will be given a score from 1 to 3 with a 3 signifying ‘always a worry’. For (ii) participants will be asked how it makes them feel, and will again have to rate this on the 3 point scale. Using visual analogue as a method of presentation has previously been used successfully in ID populations (e.g. Stigma Scale, Szivos 1991). A pilot phase will help to ensure that the materials, wording, and procedures are comprehensible to participants to help them to identify their worries. The ‘Goal Setting and Task

Performance’ of ‘The Arc’s Self-Determination Scale’ will be used to ask each participant what plans they have to manage their four most salient worries.

The Arc’s Self-Determination Scale (Goal setting and task performance section)

(Wehmeyer and Kelchner 1995). The Goal Setting and Task performance section of the Arc involves asking the participant about future plans, and looks at steps that the participant may take to achieve these future plans/goals. Scoring is as follows: zero points (the person has no plans), one point (the person identifies a plan), two points (the person identifies one or two steps towards the plan), and three points (the person identifies three to four steps). The Arc’s Self-Determination was normed with 500 adolescents (ID and non ID). It has adequate validity. Internal consistency between items is adequate (Cronbach’s $\alpha = 0.90$, Wehmeyer 1996)

General Self efficacy scale-12 (GSES-12) (Appendix C)

This scale was initially developed by Sherer *et al.* (1982) to measure self-efficacy. The original scale was refined to 12 items by Woodruff and Cashman (1993). Such scales have previously been used in ID populations (Payne and Jahoda 2004).

Background information: Information will be obtained from each participant to ascertain socio-economic status, age, gender, and stage of transition. Socio-economic status will be determined by participants’ postcodes using the Carstairs index (Carstairs 1991).

Glasgow Anxiety Scale-LD (Appendix C)

This 27 item scale developed by Mindham and Espie (2003), has good psychometric properties: test-retest reliability ($r=0.95$), good internal consistency ($\alpha=0.96$), and is reasonably correlated with Becks Anxiety Inventory ($p=0.75$). The scale takes approximately 5-10 minutes to administer.

Wechsler Abbreviated Scale of Intelligence

A formal measure of level of cognitive ability will be conducted using the Wechsler Abbreviated Scale of Intelligence (WASI-III). This is an abbreviated version of the Wechsler Adult Intelligence Scale – III (WAIS -111, Wechsler 1997). The Vocabulary and Matrix Reasoning subscales will be used in this study. Correlations between the WASI and WAIS -111 are reasonable, at 0.88 for Vocabulary, 0.66 for Matrix Reasoning and 0.87 overall.

Research and Recruitment Procedures

Recruitment: Possible classes of participants (with mild ID and non-disabled) will be approached by the researcher to provide information about the study. A participant information sheet will be given at this stage and anybody interested in participating will be advised to contact the researcher, lecturer or teacher. Informed consent will be sought if they decide to proceed (appendix B).

Procedure: All participants will be seen in the school/college with which they are familiar in one session lasting between 40 minutes to one hour. There is the possibility of obtaining the data over 2 sessions if the participant shows signs of tiredness or losing concentration.

Participants' responses will be recorded by the researcher on response sheets.

The study will be conducted in the following order:

Pilot phase: This semi structured worry interview will be piloted with two individuals who will not participate in the main interview. The aim of the pilot phase is to ensure that the semi-structured interview approach can be used to establish successful dialogue with young people with mild ID about the nature of their worries, and to check that the response format of measures works with young people with a mild ID. Administration will then take place as follows:

- 1) Open ended/semi-structured interview stage: Consent will be obtained to record the participants' responses to the open-ended questions, which will be transcribed verbatim, for coding.
- 2) Goal Setting and Task Performance section of the Arc's Self Determination Scale
- 3) General Self-efficacy Scale-12
- 4) Background information: Participants will be asked to provide information on their age, socio-demographic status and their gender. They will also be asked about transition in order to gain a broad understanding of where they are in the transition process.
- 5) Glasgow Anxiety Scale-LD
- 6) WASI-III: Following testing, participants will be required to complete 2 subtests of the WASI-III.

Settings and equipment

All data collection will take place within the college/school in which participants are recruited. Access to the WASI (including score sheets/response booklets) will be required. It is estimated that the number of participants seen in each visit to the school/college will vary between 3 and 6. Allowing for initial visits to the school/college to inform potential groups of participants about the study, and then conducting the study is likely to involve return travel to schools/colleges in Glasgow on approximately 30 occasions.

Justification of sample size

This is an exploratory investigation, however a power calculation based upon within group correlations was carried out using the ‘GPower’ calculation website. For a power level of 0.80 at the 5% level of significance for a two-tailed correlation, it was calculated that the required total sample size would be 52 (26 in each group).

Data analysis

Qualitative data of the differences between groups will be subject to content analysis (Strauss, 1987). This will begin with a descriptive account of the nature of worries that each group ruminates most about and finds most distressing. Self-efficacy and anxiety scores within groups will be subject to correlational analysis. The Statistical Package for Social Sciences (SPSS, version 17) will be used to analyse all quantitative data.

Health and Safety Issues

Researcher safety issues: Data will be collected in colleges/schools within normal working hours and will comply with standard safety procedures. When participants are being

interviewed, college/school staff will be in an adjacent room. The researcher will always have a panic alarm. No domiciliary visits will be conducted.

Participant safety issues: Confidentiality will be explained to participants at the outset and an opportunity will be given for the carer/key worker to ask questions. If any participant makes a disclosure suggesting that they themselves or others are at risk we will act professionally and appropriately, respecting limits to confidentiality. If any participant is deemed in need of medical or psychological input, this would be discussed with the participant/carers and the researcher will recommend that the appropriate figure at the school/college contacts the person's GP.

Ethical Issues: A training assessment task will ensure the task is understood. Participants will be informed that they can withdraw participation at any point and this will not affect any rights of access to support. If any participant is upset or distressed during testing, the researcher, a Trainee Clinical Psychologist, will discuss this with them in the first instance. This information will be shared with the appropriate person providing pastoral support in the school or college. In the case of significant distress or worry the researcher will recommend that the appropriate figure at the school/college contacts the person's GP. Written consent will be obtained for all participants.

FINANCIAL ISSUES: Equipment cost: 80 WASI score sheets/response booklets (£80)

TIMESCALE

March 2008: Submit proposal to University

June 2008: Proposal assessed.

Aug/Sept 2008	Apply for ethical approval
October 2008	Begin recruitment
March 2009:	Analysis
April-June 2009:	Write up research
July 2009:	Submit research to University
September 2009:	Viva

PRACTICAL APPLICATIONS

There is little research examining worry content in people with a mild ID as they make the transition from school/college, therefore these results will provide an initial investigation into the nature of worries in an ID group at this important stage. The study will also allow initial exploration of whether worries may be related to the experience of having an ID, and whether sense of self-efficacy affects people's ability to deal with worry. This exploratory research may also be of use to clinicians as worries may be predictors of emotional distress. The nature of worries in people with ID will also be of interest to schools and guidance teachers. Greater understanding of the concerns of this population at transition will facilitate guidance opportunities within school and thus help identify appropriate support. It may also be useful in future development of a formal assessment tool to assess worry in ID populations.

ETHICAL APPROVAL AND MANAGEMENT SUBMISSIONS: Ethical approval will be applied for from the local education authority in Glasgow, and Renfrewshire, then Heads

of the schools/colleges will be approached to seek permission before participants are initially approached.

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Addendum

It was initially proposed that background information would be obtained between the measures of self-efficacy and anxiety. However, piloting revealed that obtaining background information first and then completing the measures of self-efficacy and anxiety consecutively worked best. Therefore, this was changed for the main study.

Following a pilot study of the materials, it was decided not to proceed with administering the Goal setting and task performance section of the Arc Self-determination scale.

The measures were eventually piloted on 6 participants with a mild intellectual disability, rather than 2 as originally proposed.

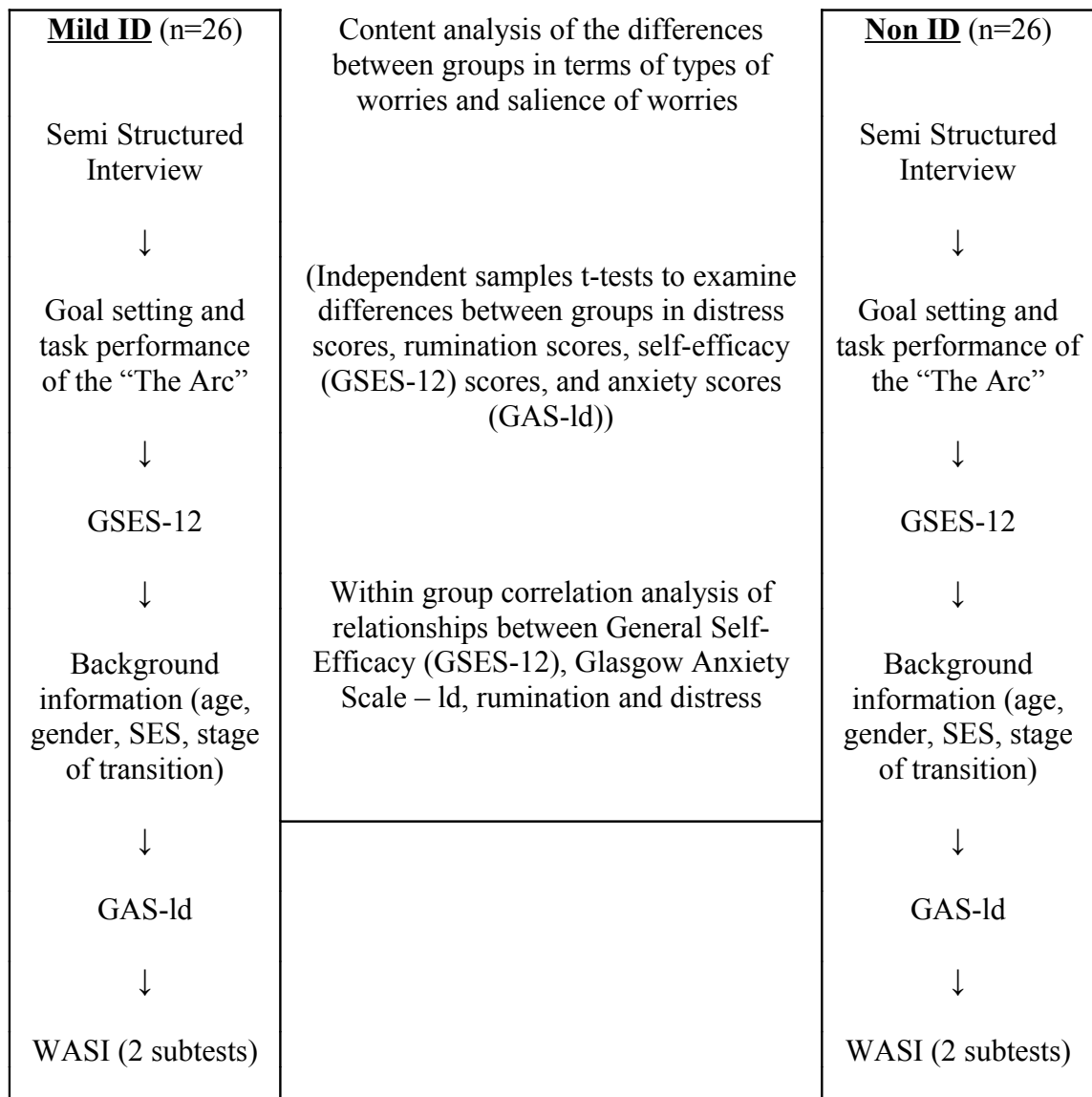
Appendix F

FLOW CHART OF PROJECT PROPOSAL

Total Participants (including pilot study: n=52)

Pilot Phase (n=2 with mild ID)

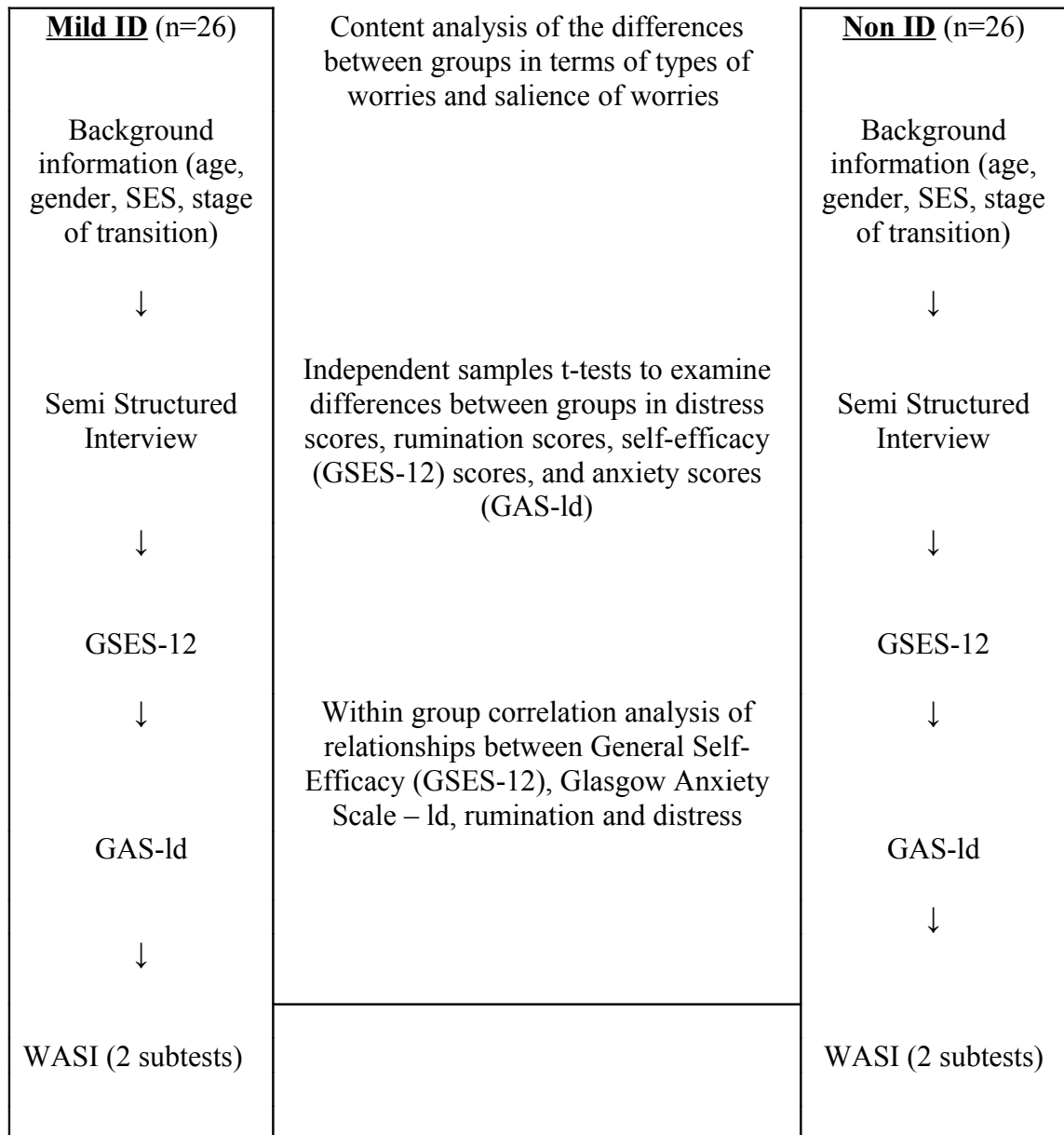
An initial pilot phase in the study will ensure that the semi-structured/open ended interview approach can be used to establish successful dialogue with young people with a mild ID about the nature of their worries, and to check that the response format works well



Appendix F

FLOW CHART OF MAJOR RESEARCH PROJECT

<p><u>Pilot Phase</u> (n=6 individuals with a mild intellectual disability)</p> <p>(individuals involved in the pilot study were not part of the main study)</p>



R&D Management Office
Western Infirmary
Tennent Institute, 1st Floor
38 Church Street
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G11 6NT

17th October 2008

Ms Marisa F Forte
Department of Psychological Medicine
Division of Community Based Sciences,
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road,
Glasgow
G12 0XH

MANAGEMENT APPROVAL

Dear Ms Marisa Forte

Project Title: A qualitative exploration of the nature of worries experienced by young people as they make the transition to adulthood.

Investigator : Ms Marisa F Forte

R & D Project Nos: PN08CO354

Ethics: 08/S0701/99

We are pleased to inform you that, based on the information provided, the above project has been granted overall **Management Approval for GG&C Health Board** and you may now proceed. This approval includes favourable Research Ethics Committee opinions.

Further management approval will be required for amendments that increase patient numbers, increase or change the test procedures or bring about a change in pharmacy requirements (if pharmacy is involved). Please contact the R&D office if you make any future amendments.

When your study ends please inform the R&D office and provide us with an end of study report for our records. The R&D office is required to provide this information to the Chief Scientist Office at the Scottish Executive for all studies that have been successfully completed.

Your project may be subject to audit or inspection by R&D or a government body. Should this occur, you will need to provide your site file containing all the documentation relating to this study i.e. Protocol, NRES, R&D application, ethical approval, overall management approval, consent forms, patient information sheets and any other relevant information associated with your study.

Yours Sincerely,

PP 
Brian Rae
R&D Manager

Primary Care Division



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Ms Marisa F Forte
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Date 28 October 2008
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 2811
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Ms Forte

Full title of study: A qualitative exploration of the nature of worries experienced by young people as they make the transition to adulthood.
REC reference number: 08/S0701/99

Thank you for your letter of 14 October 2008, responding to the Committee's request for further information on the above research [and submitting revised documentation](#).

The further information was considered at the meeting of the Sub-Committee of the REC held on 23 October 2008. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised](#), subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.



D370787

Glasgow & Clyde Primary Care, Community & Mental Health

Attendance at Sub-Committee of the REC meeting on 23 October 2008

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Liz Jamieson	Research Ethics Co-ordinator	Yes	
Mr Philip Dolan	Lay Member	No	
Dr Paul Fleming	Consultant Clinical Psychologist	No	
Mr Martin Hattie	Clinical Nurse Specialist	No	
Mr Eoin MacGillivray	Lay Member	Yes	
Dr Robert McNeil	General Practitioner	Yes	

Written comments received from:

<i>Name</i>	<i>Position</i>
Mr Martin Hattie	Clinical Nurse Specialist

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Letter of Approval from Glasgow University		22 July 2008
CV Professor A Jahoda		
Participant Consent Form: Appendix 5	Version 1	01 August 2008
Participant Information Sheet: Appendix 4	Version 1	01 August 2008
Questionnaire: Validated Glasgow Anxiety Scale LD	Appendix 2	01 August 2008
Questionnaire: Validated GSFES	Appendix 1	01 August 2008
Summary/Synopsis	Appendix 3	01 August 2008
Covering Letter		31 July 2008
Protocol	Version 1	01 August 2008
Investigator CV	Ms M Forte	
Application		01 August 2008
Participant Consent Form: Visual	Version 1	01 August 2008
Response to Request for Further Information		14 October 2008
Participant Consent Form: Visual Presentation LD Participants	Version 2	22 September 2008
Participant Consent Form	Version 2	22 October 2008
Participant Information Sheet	Version 2	22 September 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

From: [Gill Watt](#)
To: m.forte.1@research.gla.ac.uk
Cc:
Date: 01/27/09 12:38 pm
Subject: SMT Approval
Attachments:

Hi Marisa,

I am delighted to inform you that the college Senior Management Team have considered your research request and are very happy to support you and wish you all the best with project.

We will endeavour to provide you with as much support as we can and would be most interested in the outcomes of your research.

Best wishes,

Gill

Chapter 3

Advanced Clinical Practice 1:

A reflective account of the pros and cons of therapist self-disclosure: Can it hinder or enhance the professional therapeutic relationship?

Marisa Forte*

*Address for correspondence

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University of Glasgow

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Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D Clin Psy)

Abstract

The aim of reflective practise is to facilitate the Psychologist's understanding of their

own work, to enable them to grow and learn from their professional experience (Johns, 1995). Gibbs' (1988) model of reflection facilitates this by outlining a cycle of steps which can be used to guide the therapist to consider their experience within therapy.

In this reflective account I have focussed on Gibbs' (1988) model to reflect on my experience of working with a patient who had a complex medical condition I have personal knowledge of. The process of engaging the patient and the family was key to moving forward, since this patient needed support with adjustment to his condition. This reflective account discusses the pros and cons of making a personal disclosure to facilitate engagement at a time when the family were feeling that no-one could understand the impact of coping with such a complex medical condition.

Chapter 4

Advanced Clinical Practice 2

A reflective critical account of teaching on the Doctorate in Clinical Psychology course:
A useful learning experience for all.

Marisa Forte*

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*Submitted in partial fulfilment of the requirements for the degree of Doctorate in
Clinical Psychology (D Clin Psy)*

Abstract

Reflective thinking skills are crucial in the work of a good Clinical Psychologist. They give the Psychologist the opportunity to process their experiences, develop skills and grow professionally. Gibbs' reflective model (1988) is a useful tool to guide reflection

and its diagrammatical format is particularly appealing as it guides the therapist through a series of steps in the continuing reflective process.

This reflective account utilises Gibbs' model to reflect on an experience of delivering a lecture to Clinical Psychology trainees. Reflecting on my own experience of attending lectures as a trainee Clinical Psychologist allowed consideration of what elements made certain lectures stand out from others. Reflecting on different delivery formats allowed consideration of good lecturing styles and the importance of using reflection to frame my delivery style and methods of presentation while teaching other trainees.